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NATIONAL COMMISSION ON AIDS

CONFERENCE ON
HIV INFECTION AND AIDS
IN
CORRECTIONAL FACILITIES

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2 PROCEEDINGS

3 DR. OSBORNE: Let me ask people to take

4 their seats. I think we're certainly set to start,

5 we can make the arrangements following. The

6 Commission is hearing the first witness.

7 While we're getting organized, I want to

8 announce that there will be a sign language

9 interpreter there at the far end of the table, and so

10 those who would like to be able to participate in

11 having the interpretation can organize themselves

12 down that way and thank you very much for being with

13 us.

14 I also want to do a little bit of

15 Commission business. With the indulgence of our

16 guests, it was one year ago today that the Commission

17 met briefly to validate our selection of Maureen

18 Byrnes as the executive director, and we thought that

19 we should commemorate that appropriately, so we have

20 a little something for you, and we'd appreciate it if

21 you would look at it right now, at least I would.

22 Hold on it up.

23 It says "Property of New York City

24 jails."

25 (Applause.)

2 DR. OSBORNE: On behalf of the Commission,
3 thanks for a magnificent's year work and another
4 magnificent year to come.
5 MS. BYRNES: Thank you very much.
6 DR. OSBORNE: This morning we'll start off
7 with Mark Lopez as our first witness with an
8 introduction of corrections, and I will repeat this
9 from time to time, but if we could ask people who are
10 speaking--and Kenneth Castro will be talking about
11 epidemiologic perspective.
12 If I could ask the witnesses to limit
13 their remarks to at most ten minutes. We'll put a
14 little timer to go off at about eight to give you a
15 sense of how you're doing in time. This Commission
16 tends to be a lively group and asks lots of questions
17 and that will give us a chance to interact with the
18 witnesses and that's always the most helpful part.
19 If you have given written testimony, we
20 have read it if you gave it to us before, or we will
21 read it, so you can feel free to condense that part
22 of your testimony or add anything if you would like.
23 That's a good way to go.
24 Welcome, and thanks for joining us.
25 MR. LOPEZ: Thank you for inviting me.

My name is Mark Lopez, I work with the National Prison Project of the American Civil Liberties Union, a membership organization committed to the progression of civil rights and civil liberties in this country. Membership's about 300,000.

On the national level, we're made up of various projects, one of which is my own, National Prison Project, and the mandate of our office is to investigate, litigate and then monitor litigation around the country over prison conditions. In our early years, the focus was on practices and policies and conditions. In the recent years and currently, our focus is exclusively, almost exclusively, with the exception of AIDS work which I consider policy work, almost exclusively concerns conditions of confinement. We probably have pending litigation in 36 states, maybe fifteen very active right now, either going to trial or just out of trial, still in the litigation pipeline.

Myself, I'm in seven states in every part of the country. With that said, I'll get to my testimony.

A little more than 100 years ago, the

2 Supreme Court of Virginia said that prisoners are a
3 little more than slaves, and during the last five
4 years, on a number of occasions, at least three
5 justices in the United States Supreme Court have
6 questioned whether the majority of the Court was
7 turning the clock back in time when prisoners were
8 indeed treated as slaves.

9 And what happened in those hundred years?
10 Where are we now? Where are we going? I'll try to
11 answer those questions.

12 With the barbaric exception of the death
13 penalty, imprisonment is the largest power that a
14 government exercises on a regular basis over its
15 citizens. Prisons are total institutions, they have
16 a massive impact on the persons they confine. They
17 control every moment of the prisoner's day and night
18 and eliminate almost any possibility of free choice.

19 In the United States, imprisonment is used
20 far too much. The sentences imposed are far too
21 long; it discriminates based on race and economic
22 status. And many prison terms are served in
23 degrading and brutalizing conditions.

24 In 1972 the population in this country,
25 combined state and federal, was about 175,000. In

1980 it was 300,000 and change. Today it exceeds 700,000. That represents an increase in the last ten years of about 115 percent, and an increase of about twelve percent over last year. The significance of that is that our crime rates have not increased proportionately. In fact, our crime rates have been rather level. maybe 2 percent increase in crime rates over those years.

The color of our prisons is increasingly brown and black; 48 percent minorities and over 90 percent are poor, and while prisoners continue to be overwhelmingly male, there are currently 40,000 women prisoners, and their rate of increase has outpaced the male rate of increase every year since 1980.

California leads the way. There are almost 90,000 prisoners in the California system. It's doubled its population in the last five years alone. It has spent over $2 billion on prison construction in the past two years. That $2 billion represents the GNP, a greater amount of dollars than the GNP of a number of our states, or the total budget of a number of our states.

Arkansas, a small state by comparison, has 5500 prisoners, more than half the countries of

western Europe.

The states with the greatest rate of increase last year were Rhode Island, Colorado and South Dakota, all approaching 30 percent. Not surprisingly, we are actively litigating conditions in those states. You project out the 30 percent over the last three years. Each of those three states have increased at that rate in the last three years and they've nearly doubled their population in the last three years.

The resources to keep pace with that kind of growth have not been pumped in or not on time, so the current situation in those states is you've got twice as many folks packed in prisons that were already overcrowded three years ago.

This country has the harshest sentencing practices in the free world. Our per capita rate of increase is the highest, with the exception of several eastern European countries and South Africa. For every 100,000 people, over 200 people are incarcerated, and the next closest country is Canada and they're about 100.

And we keep people behind bars two to ten times as long as other countries, and the result is,

2 as I will explain, is horrendous overcrowding.
3 37 states, District of Columbia, Puerto
4 Rico, Virgin Islands are operating prison conditions
5 under court orders designed to alleviate overcrowding
6 and deleterious conditions.
7 Serious legal challenges are pending in
8 about fifteen other states.
9 What are unconstitutional conditions and
10 practices? The situation with the young first
11 offender who is assaulted and gang raped, not
12 unusual, you've all heard of it. State prisoner
13 becomes quadraplegic because of improper and
14 inadequate medical care, again, not unusual.
15 Prisoners are forced to sleep on floors in corridors,
16 happening in a number of states today; Rhode Island,
17 Delaware, Puerto Rico, Colorado, New Mexico.
18 As the population increases in these
19 prisons, resources and funds for services have
20 remained flat at the same time. Thus, in the
21 provision of medical and mental health care,
22 resources designed for let's say 1,000 people are now
23 being spread for two or three thousand people. The
24 result is people are falling through the cracks.
25 In Indiana, a case I'm actively

2 litigating, because of the unavailability of
3 psychiatric treatment, 200 people live in a forensic
4 unit where the only treatment available is the use of
5 psychotropic medication without psychiatric
6 supervision and the long-term use of restraints and
7 isolation cells.
8 Overcrowding also has an impact on the
9 environmental health and safety of prisons. I think
10 the best analogy I can think of in terms of if we
11 were to talk about plumbing or basic environmental
12 conditions, if you were to camp out a troop of boy
13 scouts in your home for a weekend or for years, you
14 can imagine what kind of effect that's going to have
15 on the plumbing and on the other conditions in your
16 house, and it does have an impact. So in Puerto
17 Rico, if you were to tour that prison, you would be
18 walking through raw sewage in the tiers adjoining the
19 cell blocks.
20 In Indiana, very similar situation, in the
21 second case I'm involved with in Indiana. 400 cells,
22 over 200 of the cells, the plumbing doesn't work. So
23 what does that mean? The person has to be pulled out
24 of a cell and use the cells that work, so the
25 problems become worse.

4

1
2 Overcrowding also has a very serious
3 impact on levels of violence. This essentially has
4 to do with the inability to properly supervise and to
5 classify and to monitor inmate activity, with the
6 conditions you've all read about in New Mexico eight
7 years ago, in Attica, and recently there was a
8 disturbance on Rikers Island.
9 The impact of the civil rights movement
10 in the 1960's and Attica in 1971 opened up the iron
11 curtain that was drawn between prisons and the
12 Constitution of this country. Historically, there
13 was a hands off approach. In the early prisoners'
14 rights cases 1962 to 1972, in a series of significant
15 Supreme Court decisions, the Supreme Court made clear
16 that the Constitution does indeed reach--
17 DR. ROGERS: Mr. Lopez, you've got a
18 couple more minutes. We have your written testimony,
19 which is very powerful. I suggest you sort of talk
20 from your heart in terms of what do you want this
21 Commission to take take way that we can do to be
22 helpful in the situations that you describe. Don't
23 worry about it, we will indeed read your testimony,
24 and it's important and don't be nervous about it.
25 Talk the way you'd like to.

2 MR. LOPEZ: If anything, I think what
3 needs to be understood that we're in a whole lot of
4 trouble in this country about prison overcrowding,
5 and the effect it's going to have on conditions.
6 We're facing a serious crisis about issues that
7 should concern all of us.
8 The ability to run a rational corrections
9 system to operate decent prisons that are safe for
10 inmates is being undermined dramatically. In the
11 past few months I or members of my staff have been in
12 about fifteen states and seen the beginning of the
13 ominous fallout from the recent Presidential campaign
14 and from recent Supreme Court decisions which are
15 stressing a "get tough" attitude and "put them away"
16 mentality. I mean to carry no grief for President
17 Bush or for candidate Dukakis. On criminal justice
18 and corrections issues, their behavior ranged from
19 foolish to irresponsible. The manner in which they
20 portrayed the Willie Horton fiasco was disgraceful on
21 both sides. However, public officials received a
22 powerful message from that campaign, be tough on
23 crime and get elected. The result for the public and
24 politicians is to cry out for more, for harsher
25 sentencing.

2 Unless there are major changes, you can
3 safely predict a doubling of the prison population in
4 many states and the federal prison system in the next
5 five or six years. Unless we develop new policies,
6 we will mortgage the future of our country to prison
7 expansion programs, we will go back to running the
8 19th century prisons that were in effect only fifteen
9 or twenty years ago.
10 Already many systems are backsliding after
11 many efforts at reform. This is due in large part to
12 the country's relentless rising prison population,
13 and it's resulted in an epidemic of overcrowding an
14 increase in prison violence and riots, a sharp
15 reduction in rehabilitative and medical services and
16 a proliferation of lawsuits challenging these
17 conditions.
18 I would sum up by pointing to two new
19 problems that will receive a good deal of attention
20 in the next immediate years. One concerns the
21 proliferation of litigation arising out of the
22 question of treatment for persons with AIDS, and that
23 will be discussed more fully by others today.
24 The other concerns the impact the current
25 sentencing laws are having in terms of the age of the

2 population. The age of the-- historically in prison
3 the average age was under 30, that's moving over 30.
4 In the not very far future it's going to move over
5 40, over 50, over 60 and there's going to be a
6 substantial body of geriatric prisoners taking up bed
7 space. With that become attendant medical problems
8 and other problems associated with providing medical
9 care for these prisoners.
10 Much has been accomplished in the last two
11 decades. Some of the human warehouses and dungeons
12 that have been the shame of our society have been
13 eliminated. Litigation and other efforts has been
14 the force that has pushed America into the 20th
15 century, but much remains to be done in the next five
16 to ten years to continue to put pressure and to
17 prevent the going backwards.
18 DR. OSBORNE: Thank you very much. That
19 is powerful testimony and succinctly put.
20 If you want to stay there, I think we can
21 get Dr. Castro to come join you at the table and give
22 his presentation and that way we could ask questions.
23
24 DR. CASTRO: Good morning. My name is Dr.
25 Kenneth Castro. I work for the Centers for Disease

2 Control. I should point out that while the Centers
3 for Disease Control do not routinely collect
4 information on the number of AIDS cases occurring
5 inmates, data are available from several yearly
6 surveys conducted associations for the National
7 Institute of Justice or NIJ and for HIV
8 seroprevalence sources collected by Johns Hopkins
9 University. Much of the data I will present here
10 today comes from the 1989 update, AIDS and
11 Correctional Facilities.
12 Because of time limitations, I will not
13 address the epidemiology of AIDS outside correctional
14 facilities.
15 Through October of 1989, 5411 confirmed
16 cases of AIDS were reported from the Federal Bureau
17 of Prisons, state prison systems and a sample of 28
18 to 30 county or city jail systems in the United
19 States. The cumulative number of such cases has
20 steadily increased from 766 inmates with AIDS
21 reported by November of 1985 to 5411 reported by
22 October of 1989, representing a four year increase of
23 606 percent. Because not all county or city jails
24 were surveyed, this figure represents a minimum
25 estimate of the number of AIDS patients among inmates

2 in correctional facilities.

3 45 of the 50 state correctional systems
4 reported at least one inmate with AIDS. However, the
5 distribution of the cases by correctional system is
6 remarkably skewed. This slide shows the range in
7 number, total number and percent of AIDS cases by
8 number of state and federal correctional systems.
9 Note in the last row that over 79 percent of inmates
10 with AIDS were reported from only seven or 14 percent
11 of the 51 systems. If we combine the last two rows,
12 11, or 22 percent of these symptoms were reported in
13 more than 50 AIDS cases each, and accounted for 87
14 percent of AIDS in inmates. I should mention that
15 1,351 of these persons with AIDS were in custody at
16 the time of the October '89 survey.

17 This next slide shows a geographic
18 distribution of inmates with AIDS in state prisons.
19 If we combine the first three rows, you will notice
20 that 81 percent were housed in New England,
21 mid-Atlantic and south Atlantic prisons.

22 This next slide shows similar information
23 from a couple of slides ago, this time for 32 city or
24 county jails, which reported 1750 AIDS patients.
25 Thirty had reported at least one patient with AIDS,

2 but again, 74 percent of all such patients were
3 inmates from only three or 9.4 percent of the 32
4 surveyed facilities.

5 Other sources of information are HIV sero
6 surveys. They provide essential data to help
7 document the magnitude of this health problem. This
8 slide shows selected HIV seroprevalence studies of
9 incoming inmates abstracted from NIJ's 1988 survey.
10 Please note the wide variation in obtained results.

11 In the time period 1987 to '88, the New
12 York State prison had 17 percent HIV seroprevalence
13 among incoming men, compared with 7 percent in
14 Maryland in 1985. In 1988, the Georgia state prison
15 had 3.2 percent of HIV prevalence in men and 2.4
16 percent in women. In general, higher seroprevalence
17 rates are found in correctional systems serving
18 geographic jurisdictions with larger number of AIDS
19 cases outside correctional facilities, such as New
20 York, Florida, California, Texas or Illinois.

21 More recently, CDC has collaberated with
22 Johns Hopkins University and NIJ in a study of
23 approximately a thousand consecutive entrants to each
24 of ten different correctional systems throughout the
25 country. Preliminary data were presented by Dr.

2 Barhouse in the 6th International AIDS Conference in
3 San Francisco. While you see here that there was no
4 statistically significant difference in HIV antibody
5 prevalence between prisons and jails, we observed a
6 wide range of results among participating
7 institutions.

8 In general, HIV prevalence rates were
9 higher for females than for male entrants. Among
10 males entering prison systems, these rates range from
11 2.2 percent to 5.9 percent. For females, they range
12 from 3.2 to 7.8 percent, and among jail systems,
13 these rates range from 2.3 to 7.6 percent for men,
14 and you can see 2.5 to 14.7 percent for women.

6

15 Again, using the same study, HIV
16 prevalence rates are shown here by gender and a
17 dichotomous age group. Males aged more than 25 years
18 had significantly higher rates than those 25 or
19 younger. For female incoming inmates, the infection
20 rates were not significantly different in these age
21 categories. However, if you took all persons younger
22 than 25 years. females had significantly higher rates
23 than men, and you could see the upper bound of the
24 ranges in that particular group being 15.6 percent
25 infection rate.

2 HIV seroprevalence rates were
3 significantly higher in non-white than white male
4 entrants, as shown in this slide. By the way, the
5 data provided did not allow us to differentiate
6 further and look at other ethnic groups. Non-white
7 female entrants had somewhat higher rates than white
8 females, but this difference is not statistically
9 significant and I suspect this is probably due to the
10 relatively lower number of women sampled. 17 percent
11 of our sample consisted of women or approximately
12 1700 of the participants.
13 Another area of concern had been HIV
14 transmission in correctional facilities. Very few
15 sources of data are available to estimate the extent
16 of this problem. In Maryland, Brewer and colleagues
17 documented HIV seroconversions in two of 393 inmates.
18 Initially seronegative at intake, for one estimated
19 seroconversion per 244 inmate years. In Nevada,
20 seroconversion occurred in two inmates while in
21 prison for an estimated conversion rate of one per
22 604 inmate years.
23 Unfortunately, the possibility that HIV
24 infection occurred before entry into the correctional
25 systems cannot be excluded in either of these

2 studies.
3 Mandatory screening of releasees from the
4 Federal Bureau of Prisons show lower HIV prevalence
5 rates or 1.5 percent than among entrants. Notice a
6 2.5 percent for mandatory screening during the years,
7 the first few months, and 2.8 percent among 10
8 percent of incoming entrants during the '88 to '89
9 time period. suggesting low transmission rates, if
10 any.
11 CDC and the Illinois Department of
12 Corrections are collaborating in a study to more
13 definitively identify the rate of HIV transmission in
14 a cohort of 2400 inmates.
15 Finally, while it appears that HIV
16 transmission occurs infrequently in correctional
17 systems, the same is not true for tuberculosis. In
18 New York State prison inmates, Dr. Braun and
19 colleagues documented a steady increase in
20 tuberculosis cases from almost 23 per 100,000 inmates
21 during the time period 1977 to 1980, to 47 per
22 100,000 inmates during the 1982-'83 time period and
23 almost 65 per 100,000 inmates during the '84 to '86
24 year time period.
25 Much of this increase was attributed to

2 reactivation of latent tuberculosis infection as a
3 consequence of the immuno suppressive effect of HIV.
4 It is widely accepted that the HIV epidemic has
5 significantly influenced the resurgence of
6 tuberculosis in various subpopulations in the United
7 States, as shown by the discrepancy between the
8 number of observed and expected cases.
9 If I may explain this slide in more
10 detail, the dotted line at the bottom part of the
11 slide shows the expected cases of tuberculosis of the
12 trends that were observed from '82 to '83 had
13 continued, and in red and in the shaded area, you see
14 the axis number of tuberculosis cases of 14,768
15 occurring between '84 and '88.
16 DR. ROGERS: Dr. Castro, I want to
17 indicate you're coming to the end of your time
18 period. This is wonderful data, I hope you will--
19 DR. CASTRO: I only have one more slide.
20 It is widely accepted that the HIV
21 epidemic has significantly influenced a resurgence of
22 tuberculosis.
23 Data on drug users attending methadone
24 maintenance program clinics have convincingly
25 demonstrated a higher susceptibility to develop

2 active tuberculosis in HIV infected than HIV
3 uninfected persons, as shown by Dr. Selwin and
4 colleagues. You see the rates of development of
5 active TB of 2.1 in the HIV positive versus none
6 observed in HIV negative.
7 The 1989 NIJ survey revealed existing
8 deficiencies in data maintenance on tuberculosis
9 positive rates and on provision of prophylaxive
10 treatment in TB, including those HIV infected
11 inmates. Correctional administrators should pay
12 particular attention to tuberculosis, because it is a
13 significant HIV associated disease, transmissable
14 through aerosols, and this poses a particular problem
15 in crowded correctional facilities where ventilation
16 is often suboptimum.
17 Thank you.
18 DR. OSBORNE: Thank you very much, and if
19 you would join us more centrally here, give us an
20 opportunity to interact with both Mr. Lopez and Dr.
21 Castro on the substance of the testimony, if the
22 Commissioners have questions.
23 Dr. DesJarlais?
24 DR. DesJARLAIS: Primarily to Mr. Lopez,
25 but Ken, you may want to comment also.

2 It's clear our prison system is in a
3 disastrous state, it's overcrowded, inhumane, it's
4 unconstitutional. It's also clear that there are
5 many prison systems in Europe that seem to be
6 functioning reasonably well.
7 Clearly, our crime rate has not been
8 dramatically reduced by the way we operate our
9 prisons. Do you see any way we can fundamentally
10 change our system to get closer to a European model
11 where something like adequate health care would be
12 possible, because the system is not in crisis, or are
13 we just sort of stuck with continual expansion,
14 continual overcrowding?
15 MR. LOPEZ: Yes, I do. One of the things
16 I want the Commission to walk away from here with is
17 the idea that these trends are reversable, though we
18 have to change national policy concerning our
19 commitment to incarcerating people.
20 As I pointed out, our incarceration rates
21 are double and triple that of western Europe and
22 there's no reason that has to be. Under the new
23 sentencing guidelines, the number of persons who went
24 to prison as first time offenders was like 100 times
25 the way it was the year before the guidelines went

2 into effect. Historically, those people were left on
3 the street in some form of court supervised capacity.
4 So unless we have a reversal in the "lock
5 them up" mentality, I don't see that happening. I
6 think we can have a reversal, because it's going to
7 be very, very expensive. It's going to at some
8 point outrage the public, you're going to see right,
9 after right, after right, and also take an economic
10 toll.
11 I would like to think when we clean up
12 relations with eastern Europe, where are those
13 military dollars going to go? Well, you need to know
14 they're going into prison construction now. That's
15 going to be very, very expensive, and we're not
16 buying up those bonds. No one here is buying up the
17 bonds to finance that. Someone is getting rich on
18 that, but it's not us.
19 Sooner or later, there's going to be a
20 price tag, there's going to be a--well, there it is.
21 Americans are going to have to wake up, A, to the
22 cost and two, to the human toll.
23 DR. OSBORNE: Scott?
24 COMMISSIONER S. ALLEN: I have a question,
25 Mr. Lopez, about the increase in interest in the

2 privitization of prisons. Does your organization
3 have some public policy concerning that? There's
4 some serious ethical questions to that and I'm just
5 curious, there's a push for privitization, and where
6 do you all stand on that?
7 MR. LOPEZ: We're skeptical, I would say.
8 As an organization, we're very skeptical, because of
9 the profit motive. Also the history of prisons, it
10 started out as a private enterprise, and they were
11 very exploitive, so drawing from that experience,
12 we're very skeptical.
13 I will say I was in New Mexico two days
14 ago at the only privately operated prison, I believe
15 it's the only privately, if not, it's one of the few,
16 and it's two years old, it's a women's prison which
17 tends to have a lot less of the problems that a male
18 prison has, but in any event, it was to their credit,
19 Corrections Corporation of America, it was running a
20 smooth ship, from what I could tell.
21 DR. OSBORNE: I just want to underscore
22 with the question, something you did say Dr. Castro,
23 but in addition to the two studies which you
24 presented which showed virtually no in prison
25 transmission, are there others that you're aware of

2 or anecdotal evidence to either raise that question
3 again or to confirm that finding?
4 And the reason I bring it up, of course,
5 is that early in the epidemic was used as an excuse
6 for a great deal of prison manipulation in order to
7 worry about in prison transmission, and I had been
8 aware of those studies. I was curious if there was
9 anything else in the works.
10 DR. CASTRO: We are now trying to complete
11 the study that I mentioned with the Illinois
12 Department of Corrections and the data are
13 forthcoming. To me it's interesting, when you look
14 at the surveys done by ACT Associates for the
15 National Institute of Justice early on, there were
16 very disparate housing policies on no scientific
17 basis.
18 However, the warden felt he or she ought
19 to do things, and over time they demonstrated a
20 tendency away from isolation, and allowing the HIV
21 infected inmates to stay with the general inmate
22 population. Part of it is, of course, because they
23 cannot afford because of overcrowding to keep them
24 isolated, and so it's most interesting that to me the
25 degree of activity is almost inverse proportional to

2 the degree of the problem.

3 Those systems with HIV infected population

4 are able to do a lot more. New York City has a lot

5 more and you see in contrast relatively much less

6 action.

7 COMMISSIONER DIAZ: Ken, maybe I missed

8 this, but you were quoting 3,600 plus actual cases of

9 AIDS at this time; no, 5,000?

10 DR. CASTRO: 5411. That's a minimum

11 estimate.

12 COMMISSIONER DIAZ: What percent of those

13 are in minority groups?

14 DR. CASTRO: Vast majority. As a matter

15 of fact--

16 COMMISSIONER DIAZ: What would you say the

17 vast majority, percentage wise?

18 DR. CASTRO: I can't give you the exact

19 percentile. I'll refer you to the latest 1989 update

20 on correctional facilities by Hammet and Mahoney, or

21 I can give it to you when we're done here, but I

22 won't make up a figure.

23 COMMISSIONER DIAZ: I'm just trying to

24 relate the number that was given by Mark in his talk

25 of 700,000 persons incarcerated at this time with 48

2 percent of those individuals are from minority
3 populations, and I just want to draw a parallel with
4 the 5,000 number you gave.
5 What is the percentage? Would you say
6 it's double that?
7 DR. CASTRO: I wouldn't want to guess.
8 I could tell you we did see in the
9 serosurveys that nonwhites had significantly higher
10 rates, and while not looking at specific racial or
11 ethnic groups. the rates of AIDS in inmates is
12 roughly about 202 per 100,000, compared to 14-1/2 for
13 the rest of the U.S. population.
14 The descriptor of most of these inmates
15 that is that by and large they're going to be
16 non-white men, many of them with a history of drug
17 use.
18 COMMISSIONER DIAZ: Thank you.
19 DR. ROGERS: Dr. Castro, we heard some
20 very potent testimony yesterday in terms of really
21 the whole prison and jail system is really
22 concentrating the HIV positive groups that are very
23 hard to get at and under than optimum circumstances.
24 If I understand you correctly, this is
25 data that's acquired not by CDC but by other groups

2 that you showed us this morning. Why in heaven's
3 name is not CDC collecting this when it's probably
4 the most critical source of infection as those people
5 move out? Why is CDC not collecting it specifically
6 on the prison population?
7 DR. CASTRO: We have some information,
8 it's not routinely obtained. It has to do--the
9 sources of information are local and state health
10 departments, and while they will give us information
11 on the residents, on the patients with AIDS, they may
12 or may not have at that time a history of being
13 incarcerated. Our source of information is not the
14 correctional systems.
15 There's a lot of interest in that.
16 DR. ROGERS: Don't you think it would be
17 wise to do that?
18 DR. CASTRO: Yes, as a matter of fact, I'm
19 sorry if I failed to reflect that we've done the
20 initial serosurvey with Hopkins University through
21 NIJ and we do intend to continue these to monitor
22 trends over time through the local health departments
23 and yes, we will have additional information.
24 DR. OSBORNE: I give the last word to
25 Diane Ahrens.

2 COMMISSIONER AHRENS: Dr. Castro, I
3 understand, and following up on David's question,
4 that your normal sources of information and
5 statistics are through the Department of Health and
6 Human Services. However, we have here really the
7 epidemic focused in on the prison system in this
8 country, both at the local and the state and the
9 federal level, and I'm just wondering, even beyond
10 the data collection system that you have, is CDC
11 doing anything else or how is CDC working with the
12 Department of Justice to establish some policies and
13 standards with respect to the correctional system
14 vis-a-vis the epidemic expressed in that system?
15 DR. CASTRO: Well, for one thing, one of
16 the--at a minimum we're trying to help collect the
17 necessary scientific basis to help drive policy,
18 public health policy. We are collaborating with the
19 National Institute of Justice in many of these
20 activities, and a lot of, I understand demonstration
21 projects are geared--I shouldn't say a lot, but some
22 of them are geared to inmate populations also,
23 looking at education and prevention activities.
24 Granted, there's a lot of difficulty
25 because it was, things have changed. It was almost

2 impossible to mention the use of condoms in inmate
3 population to go beyond just providing information.
4 A lot of these obstacles are being overcome as people
5 understand the true nature of the problem, but it's
6 still very difficult. You know, it's common
7 knowledge, under quotation, that there is homosexual
8 activity in prison, that there is drug use, but for a
9 warden or anyone who needs to make decisions to then
10 go a step further and say, well, give free needles or
11 condoms and admit to that, it poses a very serious
12 problem.
13 You know, this goes even outside.
14 COMMISSIONER AHRENS: But it seems to me
15 there are a number of issues here that go beyond what
16 one would consider controversial, like the condom
17 issues. This goes to an issue of standards of care
18 for people with AIDS in the prison system and those
19 kinds of issues that public health care needs to be
20 working with the criminal justice system to see those
21 standards are in place and I guess that's my
22 question.
23 DR. CASTRO: Absolutely, very important.
24 CDC does not get directly involved in the provision
25 of care. Other agencies within the public health

2 system have that as their primary responsibility, so
3 I know you heard this line before, it's almost, I
4 find it difficult to say, but that is a reality.
5 Our mission is not the provision of direct
6 care in this or any other setting.
7 DR. KONIGSBERG: Could I have one more
8 last word?
9 DR. OSBORNE: Dr. Konigsberg.
10 DR. KONIGSBERG: Yes, I heard that line
11 before from CDC. I also know that CDC is putting a
12 little money into a care coordination project in my
13 state, maybe I shouldn't say that publicly.
14 The point of what I want to say, I don't
15 have a question, but a comment and a recommendation
16 to CDC, continuing one that I make. I think the line
17 between the classic prevention activities and
18 treatment and care gets blurrier and blurrier,
19 especially with AIDS, but I think that's true with
20 everything else.
21 I want to re-emphasize Dr. Roger's point
22 earlier. We heard some really excellent testimony
23 yesterday that convinced me as a public health
24 physician that frankly I've been missing the boat in
25 terms of how we relate to the prison and jail system,

2 and I think there's some very important public health
3 aspects to it, and I think it would be very simple to
4 change the surveillance activities, whether we're
5 reporting AIDS cases or reporting HIV positives in
6 states where that's required to be reported in order
7 to get at that information. Although that's not a
8 substitute, I think there's something to be said for
9 the surveillance, but again, the major point I'd like
10 to leave you with is that those lines between
11 prevention and treatment are just not clear to me any
12 more.
13 DR. CASTRO: I agree with you
14 wholeheartedly, and I think if you were to look at
15 initiatives submitted for upcoming fiscal years, they
16 do reflect that sense for many of us within CDC and
17 the rest of the Public Health Service.
18 I think that the provision of care, that
19 encounter provides an opportunity for prevention
20 activities, and many of us do recognize that that
21 line is getting blurrier. I personally see it as an
22 opportunity to do better prevention.
23 DR. KONISBERG: Thank you.
24 DR. OSBORNE: Well, thank you both for
25 launching today's discussion with some very important

2 testimony. We appreciate your being here. I
3 apologize to others that we're running late, but I
4 think this was a rich and important start.
5 Let's go now to Dr. Robert Cohen, and
6 again, Dr. Cohen, you probably heard me say that if
7 you could be about ten minutes in your comments, then
8 we'll have a chance to interact, which I mentioned
9 before. Thank you for being with us.
10 DR. COHEN: Thank you for giving me the
11 opportunity to address the Commission. I have been
12 involved with medical care of prisoners since '75 as
13 a doctor, researcher, medical administrator, medical
14 expert and civil rights legislation and as court
15 appointed monitor for medical services in prisons. I
16 served for five years as the medical director of the
17 Montefiore Rikers Island Health services that you've
18 heard about yesterday and I reviewed medical services
19 in fifteen states, the District of Columbia and the
20 Commonwealth of Puerto Rico, where as of a few months
21 ago no prisoners were receiving AZT.
22 I was appointed by Federal District Judge
23 Susan Black to monitor medical services for prisoners
24 in Florida, and was recently appointed by Federal
25 District Judge Robert Ward to monitor the the medical

10

2 care in New York City's Greenhaven Correctional
3 Facility.
4 In 1986 through 1988, I was the vice
5 president for medical operations in the New York City
6 Health and Hospitals Corporation and responsible for
7 medical services for prisoners at Bellevue, Kings
8 County and Elmhurst Hospitals. I was also
9 responsible for AIDS services in the New York
10 Hospital system.
11 In 1988 I left the Health and Hospitals
12 systems stethescope in hand, to begin to practice
13 medicine again, and I've continued in clinical
14 practice, but in 1989 became the medical director for
15 the AIDS center at St. Vincent's Hospital in
16 Manhattan. In the past two years I've testified in
17 Federal Court involving the medical care of persons
18 with AIDS in Alabama, Connecticut and reviewed the
19 care of women with AIDS at Bedford Hills Correctional
20 Facility in New York.
21 I present to you my bona fides in this
22 excruciating detail so you'll take seriously my
23 observations and suggestions regarding the medical
24 care of persons with AIDS.
25 You are all experts in this terrible

disease. You will hear today about the attempts of some correctional systems to provide medical services for prisoners with HIV disease and you will hear about the failures of other systems.

What I would like you to hear, to reflect on and incorporate in your reports and recommendations is the fact that nationally that a dangerously inadequate prison health care system is being overwhelmed by two epidemics; one, the mass incarceration of poor black and Hispanic drug users and, two, the extraordinary medical demands of the AIDS epidemic.

I said before that there are no opportunities provided by the presence of so many men and women with HIV infection in our prisons. I do not mean that prisons do not have a responsibility to educate prisoners about AIDS, to provide them with comprehensive diagnostic and treatment services, allow them access in certain circumstances to clinical trials, and always to protect the confidentiality of the medical encounter. But although it might be convenient to have many HIV infected men together, prisons are not health facilities. They are violent, dangerous institutions

2 where death comes too early for the HIV infected.

3 Our prisons are terrible places. Although
4 the Supreme Court has repeatedly ruled that states
5 cannot be deliberately indifferent to the medical
6 needs of prisoners, in essence establishing a right
7 to medical care, most states are deliberately
8 indifferent to the medical needs of prisoners. Even
9 in jurisdictions where successful lawsuits have
10 brought court ordered improvements in medical
11 service, the rapid growth of the prison population
12 overwhelms the limited medical resources available.

13 You'll hear today about Alabama and the
14 Limestone prison, where all men infected with HIV
15 virus are herded into a prison within a prison,
16 forbidden contact with non-HIV infected prisoners and
17 are systematically denied access to medical care.

18 I visited Limestone on two occasions. It
19 was a chilling experience to see more than 100 men
20 separated from the rest of the prison, forbidden to
21 talk to other prisoners and to hear the correctional
22 authorities and two successive private medical
23 providers at the facility justify the establishment
24 of this quarentine on medical grounds.

25 The mandatory testing and counseling

2 procedures when I was there in 1988, and I will use
3 rough language right now, involved a testing without
4 any informed consent of all prisoners entering the
5 system. There was no notification of prisoners that
6 they were being tested and the notification process
7 involved the person in the general population intake
8 dorm being pulled out of the intake dorm and brought
9 to punitive confinement and the prisoner said, "Why
10 am I being brought to segregation?"
11 And they said, "Because you have the
12 fucking AIDS," and that was by a correctional
13 officer, that was the notification process in
14 Alabama, a state by the way, under federal
15 jurisdiction in this prison system for ten years.
16 The medical care available to these
17 prisoners was apalling. Those who were sick were
18 allowed to rot until they were beyond treatment and
19 those who would benefit from AZT or a prophylaxis
20 were systematically denied treatment.
21 A federal judge ruled that this
22 segregation was medically appropriate, and that the
23 horrible mistreatment was Constitutional.
24 New York State law recently passed on AIDS
25 in prisons forbids this kind of segregation, but the

2 New York City Department of Corrections maintains a
3 policy of segregation of prisoners with AIDS. I
4 would hope that the Commission would condemn
5 segregation, mandatory segregation of prisoners with
6 HIV infection.

11

7 In Bedford in 1988, I reviewed the care of
8 women prisoners with AIDS and repeatedly saw women
9 who were quite sick who were denied access to medical
10 care, or who, for example, had sudden episodes of
11 hypertension and acute serious neurological defects
12 and were kept in their cells, asked to walk back to
13 the infirmaries, not brought to hospitals until days
14 later when their toxoplasmosis was diagnosed.

15 In Connecticut, I reviewed the medical
16 records of many prisoners with AIDS who were
17 systematically denied access to medical care. I have
18 talked to the person working with the Department of
19 Corrections who had responsibility for treating HIV
20 disease in the prison who told me that tetracycline
21 was the treatment for pneumocystis pneumonia.

22 As you will hear, some progress was made
23 in Connecticut through the litigation process to
24 guarantee health education counseling, and medical
25 services to prisoners, but this example demonstrates

2 a critical point.

3 AIDS is a complicated disease requiring
4 sophisticated clinicians and prompt access to
5 complicated and and expensive diagnostic and
6 therapeutic services. The health care for prisoners
7 is generally so poor that there are serious problems
8 with access to the most routine or emergency medical
9 services. Followup for serious medical problems is
10 frequently delayed or ignored and access to outside
11 specialists takes from months to forever.

12 It is not possible to graft minimally
13 adequate AIDS services on to a prison health system
14 which cannot provide basic services. I'll say that
15 point two or three more times, I think it's critical.

16 A corollary is that efforts to provide
17 medical care for HIV infected prisoners must include
18 the establishment of medical care systems which can
19 provide basic care for all prisoners. I hope the
20 Commission will recognize this critical point.
21 Adding AIDS services to a Community Hospital which
22 has comprehensive diagnostic and treatment
23 capabilities is a very difficult task. Adding AIDS
24 services to non-functional prison health programs
25 will not work.

2 People with AIDS should not have to die in
3 prison. The Commission can make an important
4 contribution by urging all jurisdictions to furlough
5 or parole terminally ill prisoners. Such programs
6 cannot be AIDS specific, but should allow prisoners
7 in the final stages of this disease to die outside of
8 prison.

9 There's no question that prisoners with
10 HIV disease need access to confidential medical
11 services, access to qualified clinicians, access to
12 approved and experimental medications, access to
13 specialists, specialized diagnostic tests, to prompt
14 hospitalization when required and must not be
15 quarantined within prisons.

16 I have no doubt the Commission will
17 strongly endorse this program, as well as expressing
18 support for some program of release of terminally ill
19 prisoners with AIDS and the establishment of links to
20 community AIDS services on discharge from prison.

21 Incarceration rates in the United States
22 have risen dramatically in the past fifteen years,
23 and I provide some data similar to what Mark did.
24 It's 12,500 in 1973, 54,000 people today. In 1980,
25 the New York City jail population was 7000, and is

2 more than twenty thousand today.

3 We place millions of citizens,

4 particularly young black and Hispanic men in prison

5 and condemn them to a vicious cycle of

6 reincarceration by an unforgiving society without

7 economic oppotunity. Year after year we become more

8 repressive, more hysterical in our new puritanism, as

9 we seek to blame every social problem in our country

10 on drugs, and use imprisonment as the only solution.

11 As we imprison more and more intravenous

12 drug users, we will imprison more and more HIV

13 infected people. I don't think you need a lot of

14 slides to understand that.

15 I appreciate the work Ken is doing and I

16 can't wait to see the Illinois data, but if you

17 arrest everybody who uses drugs, then you're going to

18 have more HIV infected people in prison.

19 I strongly urge you to recognize the

20 stupidity of our current policy of incarcerating more

21 and more HIV infected individuals by choosing mass

22 imprisonment as our response to the use of drugs.

23 There are two preferable alternatives to

24 the current epidemic of mass incarceration: Drug

25 treatment should be available to all who want it and

2 there should be legalization of drugs. Drug
3 treatment is cheaper and more effective than
4 incarceration in changing behavior and modifying the
5 course of the AIDS epidemic, which is the task of
6 your Commission. Drug treatment at the present time
7 is unfortunately not as effective as we need it to
8 be. It's like AIDS treatment in that respect, but
9 has greater potential than imprisonment which
10 wrenches individuals from their communities and
11 creates a huge class of unemployable men who are more
12 likely to use drugs.
13 Legalization must be--I say "men," because
14 we're talking about 95 percent men in this
15 population. Clearly, there are many women and as you
16 have heard or will hear, the percentage of women who
17 are infected that are incarcerated is greater than
18 men.
19 Legalization must be seriously considered
20 in any strategy for coping with drug use. If heroin
21 had been legal and users had access to sterile
22 needles and syringes, the epidemic probably would not
23 have spread rapidly within this population.
24 Is our country ready for legalization? I
25 actually think so. Prohibition continues to fail

12

2 miserably and tragically and at unbearable cost.

3 Both of these alternatives should be

4 carêfully considered by the Commission.

5 Implementation of these alternatives will make a

6 substantial contribution to controlling the AIDS

7 epidemic. Continued mass imprisonment will do

8 nothing to stem the spread of this disease.

9 It is difficult to provide medical care

10 for prisoners. It is essential that medical care be

11 provided for prisoners. Care for prisoners with HIV

12 disease is complex, expensive and requires well

13 trained clinicians. It cannot be grafted on to a

14 non-functional prison health care system, it just

15 won't work.

16 The components of the system are the same

17 as those for non-prisoners; the extra difficulty

18 involved in providing complex medical services in a

19 non-health care space. This difficulty cannot be

20 minimized. It is magnified beyond solution, by the

21 rapid increase in prison population with an

22 increasing prevalence of HIV infection.

23 The Commission can provide needed

24 leadership by linking the provision of adequate care

25 of prisoners with AIDS to a rethinking of our present

2 national policy of mass incarceration.

3 Thank you for this opportunity, best of

4 luck in your deliberations and your leadership is

5 valued by all fighting against this epidemic.

6 Thanks.

7 DR. OSBORNE: Thank you, that's wonderful

8 testimony, we appreciate it.

9 Questions from the Commissioners? Diane?

10 COMMISSIONER AHRENS: Yes, unless I

11 misunderstood yesterday's testimony, when we met with

12 some of the health officials at Rikers Island, page 4

13 in your testimony indicates that the New York City

14 Department of Corrections maintains a policy of

15 segregation of prisoners with AIDS. That was in

16 contrast to what I thought I heard yesterday, and I'm

17 wondering if you would want to expand a little bit on

18 that?

19 DR. COHEN: Yes, I would. I confess to

20 being present at the conception of that policy, which

21 I expressed my apologies and regrets. There is a

22 policy of segregation on Rikers Island of people with

23 CDC defined AIDS. It is true, as Dr. Braslow could

24 tell you, that he knows many patients with CDC

25 defined AIDS who are not segregated, but there is a

2 segregated dormitory for the care of prisoners with
3 AIDS, people who are diagnosed with AIDS are sent
4 there, they cannot be discharged into the general
5 population, and that is the policy right now. HIV
6 infection is treated throughout the prison.
7 COMMISSIONER AHRENS: When they described
8 the medical facility there, which of course we did
9 not see, they did say that because people with AIDS
10 require greater provision of care and nursing
11 service, et cetera, they are in a separate room in I
12 take it the infirmary, but that's a little different
13 than saying they segregate people with AIDS.
14 DR. COHEN: They do segregate people with
15 AIDS. I care for hundreds of people with this
16 disease. They're my patients. They work, they may
17 not work, they don't require infirmary housing.
18 When people are required to be in an
19 infirmary it's critical that every prison medical
20 care system like Rikers must private infirmary style
21 services for people with AIDS any disease who need
22 them, but there's not reason for people who don't
23 need medically intensive services to be segregated
24 within that, and that's my point.
25 COMMISSIONER DALTON: Dr. Braslow? I

2 wonder if Dr. Braslow could come to the microphone
3 for just a second?
4 DR. BRASLOW: I'd be glad to clarify that,
5 if I may.
6 DR. ROGERS: You can even sit next to your
7 colleague if you want.
8 DR. BRASLOW: There is no segregation for
9 people with HIV infection. There is a dormitory
10 within an infirmary on Rikers Island which the policy
11 is that it is used to house people with CDC defined
12 AIDS. I feel that that's medically totally
13 inappropriate, and we have tried to not follow this
14 policy by not admitting all people with CDC defined
15 AIDS to this infirmary, if their medical condition
16 warranted that situation.
17 We also have admitted some people who had
18 not reached the stage of CDC defined AIDS, but who
19 did require the medical level of care that could be
20 provided there. We have admitted people there. As
21 Dr. Cohen said, there's extreme difficulty
22 discharging people from this dormitory, because it is
23 widely known as the AIDS dormitory, and therefore,
24 there is a perception that if people are discharged
25 from there, that they will be victimized.

13

2 COMMISSIONER DALTON: Let me just follow
3 up for a second. Hi.
4 I take it then when you say that that's a
5 dormitory in which the policy is to place people who
6 have CDC defined AIDS, you're talking about people
7 who even during those periods in which they are not
8 experiencing symptoms that require them to be in an
9 infirmary, correct?
10 DR. BRASLOW: That's correct.
11 COMMISSIONER DALTON: And your latter
12 point about there's a perception that if they're
13 released from the, quote, aids dorm to the general
14 population, there may be some difficulty, that seems
15 somewhat inconsistent with some of the testimony
16 we've heard yesterday that education that's proceeded
17 so far in the jail system that in fact inmates who
18 were known to have AIDS were not at risk.
19 DR. BRASLOW: It's my belief that people
20 who are in Dorm 4, which is what the dormitory is
21 known as, could be discharged from there, and I feel
22 it would be worth doing and am not concerned about
23 the possibility of recriminations against them.
24 The Department of Corrections feels to the
25 contrary, and therefore that is the philosophy, that

2 is the official policy.
3 COMMISSIONER DALTON: Thank you. I do
4 have a question for Dr. Cohen.
5 You talked about the need for a policy
6 nationwide of compassionate release for inmates who
7 are terminally ill. I recently had the experience of
8 trying to get an inmate released from the federal
9 system who had full blown AIDS. He came into the
10 authority of the parole board because of the point at
11 which he had been incarcerated and several times he
12 was told, "When you have five to ten days to live,
13 get back in touch with us."
14 Which raises of question of what do you
15 mean by terminally ill, how do you define that? DOes
16 anyone who is HIV infected or has full blown AIDS
17 qualify?
18 So could you put a little flesh on that?
19 DR. COHEN: I'll try to. It's not an easy
20 problem, it's something the prison system has been
21 coping with well before this epidemic.
22 When I was in Illinois, I think that's
23 when Governor Kerner was released from prison, he was
24 suffering from cancer. The criteria would be
25 medical, think would involve some guess, which of

2 course is all one could do about life expectancy, and
3 would be on the short end rather than the long end,
4 but I think we would be talking months rather than
5 days.
6 It would certainly have to have a review,
7 some judicial review relative to the charges, because
8 the social--because the popular response to release
9 of people would be a function of the crimes. It
10 would reflect their degree of capacity at the time,
11 and people who were dependent, incontinent and with
12 severe neuropathy and can't walk don't serve any
13 function by being in prison, and they can be
14 discharged.
15 New York City in an easier mode has a
16 system of removing people, it's called and ROR,
17 release on recognizance, maybe you heard about it
18 yesterday, a program where those kinds of criteria
19 are used for people who are awaiting trial, and they
20 are taken out of the system.
21 There are tremendous financial aspects to
22 this issue, because if you can get someone out of
23 prison, they then become, their medical care is then
24 paid for by the Medicaid or other systems, and the
25 cost of incarceration and guarding is reduced.

2 I hope that's responsive to your question.
3 I mean, I could help anybody who wanted to write such
4 a policy and I have in the past. Those are the
5 elements of it.
6 COMMISSIONER KESSLER: Dr. Cohen, I want
7 to applaud you for your passion and also your
8 courage. I think as you were two-thirds of the way
9 through your talk, I was sitting here thinking,
10 somebody's going to have to raise this issue of
11 legalization and I was about to ask you that when you
12 dropped it, and I'm glad you did.
13 It's difficult I think for us today to get
14 into this full blown, but I regret that Mr. Cohen
15 isn't here, because I'd like to ask him now, too.
16 Not Cohen, but Lopez.
17 DR. OSBORNE: He's here.
18 VOICE: He's hiding.
19 COMMISSIONER KESSLER: Okay. It's
20 probably the most controversial thing that--
21 certainly takes the heat off condoms, but would you
22 like to spend a few minutes kind of visualizing for
23 us publicly what your concepts would be or what you
24 think might be the ingredients in a legalization
25 program?

2 DR. COHEN: I could try. There are
3 probably others within your own group who may be
4 better at that.
5 The basis for the legalization program
6 would be a recognition of the failure of prohibition.
14
7 I think that's the critical step, and that's
8 been--that has been true for as long as I can
9 remember and have reviewed the issues.
10 I think that the models that have been in
11 use in the Netherlands and in England have been
12 reasonably successful, that would be posing a
13 medicalization model of availability of drugs. I
14 can't actually imagine something which is not State
15 regulated, and think that such things should be State
16 regulated.
17 The profits in the system should be
18 limited and they should go towards medical and
19 educational and other social needs of this country,
20 so I would propose a federally regulated system of
21 distribution with possibly some medical components
22 for people who are addicted and are seeking
23 maintenance.
24 DR. OSBORNE: While you're commenting,
25 would you weave crack into your comments, because I

2 get stopped periodically about that stage by people
3 who point out that does raise different issues from
4 injectable drugs.
5 DR. COHEN: I think crack may raise some
6 different issues from injectable drugs. I believe
7 that the data on crack is not in, I believe that
8 everybody in this room over the past three or four
9 years has been subjected to an unbelievable barrage
10 of information from the Partnership for a Drug Free
11 America, et al, on drugs, which I am a little tired
12 right now, because I spent much of the night with my
13 six week old baby daughter, and I was reading the
14 back of the Times the other day, which gave me a
15 story to read for her when she's bigger, about the
16 meanies in her schoolyard who are going to give her
17 marijuana.
18 I'm not sure what the real data on crack
19 is. There's no question that there are people, many
20 people who use crack who lose control on it. I don't
21 know if those numbers are anywhere near the number of
22 people who use alcohol and lose control on it. And I
23 don't know if the availability of the drug and the
24 cost--if the availability of the drug were controlled
25 like alcohol whether or not we would have anywhere

2 near the problems that we have with alcohol, and I
3 say this being anti- prohibitionist, because of the
4 failures and the social cost of prohibition and the
5 creation of extraordinary crime by people fighting
6 for the profits of the drug industry.
7 So that's all I can say. I really do not
8 think there's a huge amount of data on crack and I
9 doubt it would be anywhere near as large as the
10 problem we have with legalized alcohol.
11 DR. DesJARLAIS: Obviously, the
12 legalization of drugs goes beyond just what this
13 Commission is chartered to consider, but I think I
14 would have to strongly agree with you that if
15 anything is going to lead to the decriminalization of
16 drugs in this country, it will be the failure of our
17 incarceration system to control drug related crime.
18 The specifics of a decriminalization
19 system, whether it would be State controlled, whether
20 you would allow for-profit companies, whether you
21 would have--what drugs you would do with various
22 levels of decriminalization, I mean, clearly, the
23 Dutch system does not legalize drugs, and they make
24 that very, very emphatic when you visit there, that
25 it's not a legalization system and that they treat

2 marijuana very differently from heroin and cocaine.

3 All that becomes very complicated and

4 probably the biggest difficulty that the advocates of

5 legalization or decriminalization face is the

6 complexities and difficulties of working out what you

7 would do for various drugs that no one seems to be

8 able to work through what would appear to be a viable

9 system for decriminalization.

10 DR. OSBORNE: Harlon has the last word on

11 that.

12 COMMISSIONER DALTON: This obviously isn't

13 a chance to have a full blown discussion on this

14 topic. I did want to just say, thank you also for

15 raising it, and point out just how recent the

16 criminalization of drug use is in this country, and

17 it's a question of criminalization versus

18 decriminalization, rather than legalization.

19 There's nothing God given about the way of treating

20 drug use in the way that we do.

21 DR. OSBORNE: Well, you have raised an

22 important issue, and I very much appreciate the power

23 with which you testified about it. We will not walk

24 away from it completely in future discussions, I'm

25 sure.

2 Thank you very much, and I think we should
3 proceed to Dr. Moritsugu, Assistant Surgeon General,
4 Medical Director, Federal Bureau of Prisons.
5 Thank you for your patience.

15

6

7 DR. MORITSUGU: Good morning, and in the
8 interests of some physiologic needs, I know you have
9 all been sitting for a long time without a break and
10 I am willing, if you would like to postpone my
11 testimony until after a break. It is at your
12 pleasure. I am here for the afternoon.
13 DR. OSBORNE: Thank you, that sounds like
14 a good idea. Some of my Commissioners in particular
15 say its sounds like a good idea, so we'll take a
16 brief break.
17 (Brief recess.)
18 DR. OSBORNE: I think we better go ahead
19 and get started, in the interests of time.
20 I gather that the line to the telephone is
21 a little bit longer than we expected, but thank you
22 for being patient with us, and we will proceed with
23 Dr. Moritsugu, who has kindly agreed to kind of cross
24 reference the written testimony, which we will have a
25 chance to look at at our leisure, and to take most of

2 the time to interact with us.

3 Before I forget to do so, Dr. Castro has

4 mentioned to me that he has put a set of the CDC

5 policies with respect to tuberculosis and

6 correctional facilities somewhere along the table

7 there, for those of you who are interested in that

8 additional briefing material, which was not

9 necessarily included with what you got.

10 Thank you, doctor.

11 DR. MORITSUGU: Thank you very much, Dr.

12 Osborne and Commissioners.

13 I first would like to bring you greetings

14 from J. Michael Quinlan, who is the director of the

15 Federal Bureau of Prisons who was unable to be here.

16 He was specifically invited to presented to you, he

17 has a very intense personal interest in this issue

18 and has testified previously before the Commission on

19 this very issue.

20 As I have been introduced, I will also add

21 for the record a copy of my bona fides, so I will not

22 need to go through that in extensive detail, short of

23 saying that as a career officer in the U.S. Public

24 Health Service, I am currently the Medical Director

25 for the Department of Justice Federal Bureau of

2 Prisons, a system of prisons encompassing 65
3 institutions and 57,000 inmates at this point, and
4 growing. It is a federal system and it addresses
5 those individuals who are incarcerated principally
6 for federal crimes.
7 I appreciate the opportunity to provide
8 the Commission an overview of our policies on HIV
9 infection and AIDS at your hearings, and I will
10 summarize my prepared comments which I believe you
11 have for the record.
12 The basis of the policies with regard to
13 HIV infection within the Federal Bureau of Prisons
14 has to do with a balanced approach between the rights
15 of individuals who are HIV positive and the rights of
16 uninfected individuals within the context of very
17 complex medical, legal and ethical issues. We
18 believe that a balanced approach is possible, it is
19 consistent with all contemporary advisories of the
20 Centers for Disease Control and in fact was used as a
21 model for the correctional settings in the June 1988
22 report of the President's Commission on the HIV
23 epidemic.
24 The basis on which we establish our entire
25 policy is education and not segregation.

2 Our HIV program is a systematic approach,
3 which targets four important areas; education,
4 testing, counseling and treatment. We place a great
5 deal of emphasis on prevention as exemplified in some
6 of our initiatives. With regard to our education
7 programs, we have programs that are addressed both
8 towards staff as well as towards inmates. We utilize
9 numerous media including lectures, discussion groups,
10 written materials and videotapes, some of which are
11 uniquely prepared for us, and others we have been
12 able to obtain licenses from, for example, public
13 broadcasting's systems, in other words, to make
14 copies of the AIDS Quarterly, which we distribute
15 every three months to every single one of our
16 institutions for showing not only to staff, but also
17 to inmates.
18 The principle, again, that we utilize is
19 one of universal precautions and we educate very
20 intensively along the lines of universal precautions.
21 As far as testing is concerned, we have
22 several categories for testing inmates. First, a
23 sample of newly committed inmates which we follow on
24 a regular basis to monitor the epidemiological
25 prevalence within the prison system.

2 Two, all inmates prior to release.

3 Three, all inmates who ask to be tested.

4 Four, all inmates who display clinical

5 signs of HIV infection.

6 And fifth, any inmate who displays what we

7 consider as predatory and promiscuous behavior.

8 Regarding our sample of newly committed

16

9 inmates, this entails testing a certain proportion of

10 all newly committed inmates every year, whom we then

11 follow every six months if the individual tests

12 seronegative. Again, this is to measure our intake

13 rates as well as to ascertain whether or not there is

14 in fact any transmission within our system.

15 We have found a very small number of

16 individuals who have seroconverted while within our

17 care. That is, approximately 14 individuals who

18 initially tested negative who on subsequent testing

19 tested positive. However, nearly every single one of

20 those individuals who seroconverted, sero- converted

21 by the first six month retest. There is a very

22 significant epidemiological implication there, that

23 it is very possible and probable that the initial

24 test occurred during the latency period.

25 We require all inmates to be tested prior

2 to being released. The information is considered
3 strictly confidential, and is released on a need to
4 know basis. Identification of blood samples are by
5 number, rather than by name. The individuals who
6 normally are considered need to know are the warden
7 at the institution, the clinical staff, psychology
8 services staff and the inmate's unit manager. At the
9 time that the inmate is nearing release, we notify
10 the U.S. Probation Office, and where this is post
11 release supervision, we do notify the community
12 programs manager in the case of the halfway house
13 placement.
14 Lest you think that all we do is test, we
15 also provide pre and post test counseling, and that
16 is every individual who is tested, whether by
17 volunteer or by random sample, the individual is
18 counseled prior to the test being administered, and
19 subsequent to the test being administered, when the
20 results of the test are reported to the individual
21 inmate.
22 As part of our perspective that we have a
23 responsibility not only within the institution, but
24 as well to the community at large, when we do have an
25 HIV positive test reported, we also report that

2 information to the respective board of health in the
3 state in which our institution is located, consistent
4 with state and local laws. We encourage HIV positive
5 inmates to notify individuals who may have been
6 placed at risk as a result of the inmate's
7 activities.
8 As far as treatment is concerned, we
9 provide or attempt to provide state of the art
10 medical care consistent with community standards. We
11 provide AZT and aerosolized Pentamidine to those
12 inmates for whom there is a clinical indication.
13 Furthermore, we do not segregate HIV positive
14 inmates. Those inmates remain in the general
15 population.
16 All institutions can provide non-acute
17 care through resources which exist within the
18 existing facility, or through contract services
19 outside that facility. For those individuals
20 requiring hospitalization, we refer those individuals
21 to inpatient care at one of our medical referral
22 centers; for males, at our Medical Center for Federal
23 Prisons in Springfield, Missouri, as well as our
24 Federal Medical Center in Rochester, Minnesota, which
25 parenthetically is affiliated with the Mayo Clinic,

2 and for females at our hospital in Lexington,
3 Kentucky.
4 We do provide prophylactic AZT consistent
5 with CDC recommendations, and we have an intensive
6 program which encourages inmates to self identify and
7 to volunteer for testing if they have not been
8 previously identified and if they believe that they
9 have engaged in high risk behavior that could cause
10 them to be HIV positive.
11 Part of our system of health care includes
12 a hospice program, which is located at our Medical
13 Center for Federal Prisoners in Springfield and a
14 smaller hospice program in Lexington, Kentucky. The
15 program uses community hospice leaders, staff
16 chaplain and staff psychologist who trains inmate
17 volunteers to serve as hospice counselors.
18 Individuals who are within the federal
19 prison system do have an opportunity to request early
20 release. One of your Commissioners has already
21 commented on that, and I am not familiar with that
22 request personally. However, I do need to comment
23 that those requests for early release have been
24 extremely rare. In the two and a half years of my
25 tenure as medical director, I believe that I have

2 actually seen perhaps three requests that have
3 actually come to me, because I am ultimately
4 responsible for making the recommendation from the
5 Federal Bureau of Prisons, and in each of those
6 instances, because the criteria met what we felt were
7 appropriate, we did in fact recommend to the parole
8 commission or to the courts an early release.
9 I should comment that we in the Federal
10 Bureau of Prisons do not have unilaterally the
11 authority to release an individual who is serving a
12 sentence. That authority is retained by the courts
13 or by the U.S. parole commission, and subsequent to
14 the phasing out of the U.S. Parole Commission, it
15 will go back to the courts.
16 I have mentioned earlier that we do
17 mainstream all of our HIV positive individuals. We
18 do not segregate. Our emphasis on education,
19 universal precaution, and what we believe is
20 professional management of HIV positive inmates has
21 rendered in our opinion isolation unnecessary. We do
22 and we have the authority to place inmates who are
23 displaying predatory or promiscuous behavior in
24 administrative detention. Those situations are
25 extremely rare. Within the last three years, I

17

2 believe that we have less than two dozen individuals
3 who have in fact qualified for administrative
4 detention along these lines.
5 They do not remain in administrative
6 retention forever. They are reviewed on a regular
7 basis, and in fact at this point we have
8 approximately eight individuals who are so
9 segregated.
10 We do not allow inmates to participate in
11 medical experimentation. However, we do allow access
12 to extended access programs. That, however, is an
13 extremely limited situation, it requires my personal
14 review and personal approval, and that is to protect
15 the inmates from unwarranted, unnecessary medical
16 experimentation, and this is across the board, it is
17 not only within the case of HIV positive inmates.
18 In summary, the total approach we have
19 taken in developing our HIV policy within the Federal
20 Bureau of Prisons, which we believe is an integrated
21 policy, is consistent with our overall mission in
22 health services, and that is to provide up to date
23 compassionate care that is consistent with community
24 standards, care that is both available as well as
25 accessible to the inmates, which balances the

2 responsibility between we as the custodians and care
3 providers, and the inmates who are also our patients
4 and our clients, based upon a very strong program of
5 education and not segregation.
6 I have quickly gone through my prepared
7 testimony, hopefully summarizing for the
8 Commissioners what is written before you. I thank
9 the Commission for this opportunity to explain our
10 program regarding this very, very severe problem, and
11 I am here to respond to any questions or comments
12 that you might have.
13 DR. OSBORNE: Thanks very much. Harlon
14 Dalton.
15 COMMISSIONER DALTON: Dr. Moritsugu, I
16 have questions in three areas. One has to do, this
17 will be no surprise, with your compassional release
18 program. Second has to do with what you characterize
19 as state of the art treatment for inmates who are HIV
20 positive and the third has to do with testing.
21 The case I mentioned was a case involving
22 the parole board. You indicated, though, that you
23 were the final decision maker with respect to
24 compassionate release requests. Does that mean that
25 inmates who still come under the parole system, that

2 the parole board then asks your opinion about whether
3 there should be compassionate release or do they make
4 the decision on their own?
5 DR. MORITSUGU: Let me be very careful,
6 because as you were making your statement there was a
7 statement there which may not be correctly
8 interpreted.
9 I am not the final determinant for the
10 Commission. I am the final determinant in making a
11 recommendation from the Federal Bureau of Prisons to
12 the director of the Federal Bureau of Prisons as a
13 surrogate to the U.S. Parole Commission. In other
14 words, we are in an advisory or recommending role,
15 the U.S. Parole Commission actually has the authority
16 to act.
17 Now, the question that you are
18 specifically asking, does the U.S. Parole Commission
19 turn to us for our recommendation, and the answer is
20 yes, they do consider our recommendation very, very
21 strongly. The recommendation, the review that we
22 make is based upon an initiation of such a request
23 for early release by the inmate, reviewed by
24 institutional staff with a recommendation that
25 ultimately comes to my desk for a review, which then

2 goes to the Parole Commission.

3 COMMISSIONER DALTON: If I were to send

4 you documentation of an inmate at Danbury prison

5 whose prison doctor recommended that he be released

6 early because of his terminal AIDS, and if I sent you

7 documentation from the Parole Commission twice

8 saying, "Come to us when he has five to ten days

9 left," would you use that as the basis for some

10 further education of the Parole Commission around

11 HIV?

12 DR. MORITSUGU: I would be happy to review

13 the case that you're describing. I'm not personally

14 familiar with it, since we haven't used any names in

18

15 this discussion, nor do I think it's appropriate for

16 us to do so.

17 COMMISSIONER DALTON: Your education

18 function, does that include educating the Parole

19 Commission?

20 DR. MORITSUGU: It is not within our

21 specific authority to educate the Parole Commission,

22 but I would say that our interaction not only with

23 the Parole Commission, but also with the courts and

24 other correctional institutions, that we do have an

25 ancillary educational role.

2 COMMISSIONER DALTON: Now, the same inmate
3 had been on AZT in the prison and that worked
4 perfectly well, except for the minor fact he couldn't
5 have a timer because that would let the inmates and
6 guards know he had AIDS, but let's leave that aside.
7 After a few years on AZT that drug became
8 ineffective for him and he wanted to try DDI, and he
9 was told that he could not be put on DDI within the
10 Bureau of Prison system because DDI is, quote,
11 experimental, or in any event non-FDA approved.
12 The impression I got from your written
13 testimony is that the Bureau of Prisons will allow
14 extended access to non-FDA approved drugs if in fact
15 approved drugs proved ineffective, et cetera, et
16 cetera. Was this just a glitch in the system in this
17 person's experience?
18 DR. MORITSUGU: No, it's not a glitch in
19 the system and I presume that the case occurred
20 several months ago. As you are aware, what we are
21 dealing with is a very fast moving target and
22 policies in science are evolving at a very, very
23 rapid rate. At the time that that policy may have
24 been applied--
25 COMMISSIONER DALTON: In May of this year.

2 DR. MORITSUGU: In May of this year, we
3 did not and we have not yet sent out clear guidance
4 regarding the utilization of DDI, because we are
5 reissuing the entire policy come September-October of
6 this year. It's prepared to be released in the next
7 month and a half.
8 Prior to that time, it was an articulated
9 policy of the Bureau not to allow such extended
10 access, because at that time we did not feel that DDI
11 was appropriate and safe for use. Recently, we have
12 gotten new information, evolving information, and we
13 are re-examining that, and I expect that we will
14 allow extend access.
15 COMMISSIONER DALTON: And the third set of
16 questions has to do with testing.
17 Those incoming inmates that you test for a
18 two-month period, is that with or without informed
19 consent? Is that mandatory testing of the entire
20 cohort that comes through?
21 DR. MORITSUGU: Every individual who is
22 tested knows that he or she is being tested. I
23 suppose that one can play semantics and say is it
24 mandatory testing, yes, it is expected that if you
25 are in the cohort you will be tested. However, it is

2 a random testing as opposed to everyone being tested,
3 but in fact, we expect those individuals who are
4 randomly identified to agree to test.
5 COMMISSIONER DALTON: And given the fact
6 that you follow up periodically, I gather this is not
7 a blinded testing, you know who these inmates are and
8 what the status is?
9 DR. MORITSUGU: That's correct, we are
10 aware of that, as I've described to you, with very
11 strict confidential controls on the information.
12 COMMISSIONER DALTON: And you test all
13 inmates prior to release? As I recall when this
14 policy was first announced by then Attorney General
15 Ed Meese, he was asked by a reporter why, and his
16 answer after some hesitation was, well, perhaps these
17 people might be seropositive, and then we would want
18 to maybe not release them or we might want to warn
19 possible future employers.
20 Now, I gather from your written policy
21 that that, at least the official policy of the Bureau
22 of Prisons is to not take into account sero status in
23 making release decisions, but that still leaves a
24 question of why do this? Why do you test inmates
25 prior to their release and why do you inform the

2 Probation Department?

3 DR. MORITSUGU: Well, first you asked a

4 series of questions there, and let me see if I can

5 remember them seriatum.

6 Number one, the purpose of our testing all

7 individuals prior to release has been our belief that

8 prior to releasing individuals into the community, we

9 do have a certain degree of responsibility to notify

10 state health departments regarding serostatus, also

11 to provide individuals who may have been within our

12 system an opportunity to know what their serostatus

13 is.

14 Now, with regard to the statement that you

15 implied or stated, I'm not familiar with then

16 Attorney General Meese's comment about not releasing

17 individuals, my testimony is accurate, and that is

18 that the determination of whether to release or not

19 to release an individual is not predicated upon sero

20 status, because we do not have the legal authority to

21 keep an individual a minute longer than the

22 expiration of a court sentence.

23 However, we do have the authority to

24 determine whether an individual will be released, at

25 what point an individual will be released to a

2 halfway house. Whether or not an individual exhibits
3 certain positive social behaviors, and I say this in
4 quotes, that piece of information, whether an
5 individual has consented to a prerelease testing, and
6 to notifying a significant other, that can be
7 considered, and I do not say that it is in every
8 instance considered by those individuals making early
9 community release decisions.
10 COMMISSIONER DALTON: Let me, so we can be
11 clear about this, assuming that an inmate, quote,
12 "consents," and I think we can agree that this isn't
13 really an issue of consent or not consent prior to
14 being released, assuming an inmate is tested and
15 turns out seropositive. Can that be taken into
16 account in deciding whether or not and when to go
17 into community release, release into a halfway house?
18 DR. MORITSUGU: If you're asking me from
19 the standpoint of the Bureau of Prison's policy, the
20 answer is no, that will not be taken into
21 consideration.
22 COMMISSIONER DALTON: But you do inform
23 the halfway houses of the sero status?
24 DR. MORITSUGU: After the decision to
25 release.

2 COMMISSIONER DALTON: And in practice, I
3 take it these are private halfway houses for the most
4 part, rather than government facilities?
5 DR. MORITSUGU: That's correct.
6 COMMISSIONER DALTON: And do such halfway
7 houses uniformly take such inmates who are
8 seropositive; do they reject inmates who are
9 seropositive? What is the practice?
10 DR. MORITSUGU: I really can't answer that
11 question for you, because I really am not familiar
12 with it at that point. I do know that we have a
13 spectrum of awareness in the community, just as there
14 is a spectrum of awareness in the professional areas
15 and within the Federal Bureau of Prisons.
16 We have had a couple of instances where
17 there has been resistance in accepting an individual
18 who has been known to be HIV seropositive. Again, we
19 attempt to work with those institutions to educate
20 them, that just because an individual may be
21 seropositive does not create a higher or lower risk
22 of infection.
23 DR. OSBORNE: This obviously is something
24 that we would like to spend more time talking about,
25 and I do have a letter that brings up a case in

2 point, which we certainly don't want to discuss in
3 its particulars because of confidentiality, but I
4 might ask Mr. Dalton to look at it and get a chance
5 to talk with you before we lose your valuable time,
6 so we can pursue the issue a little bit further in an
7 appropriately confidential context.
8 Harlon, take a look at this.
9 Eunice, you had a last question. I'm
10 sorry we're having to be so brief.
11 COMMISSIONER DIAZ: Very brief questions.
12 Thank you, Ken, for being here and taking time from
13 your schedule to give such valuable information.
14 My first question, I would just like to
15 relate some of the facts that you gave about AIDS in
16 federal prisons. Do the statistics in any way
17 parallel the demographics of AIDS in communities, the
18 kind of information or do not?
19 DR. MORITSUGU: Yes, the statistics that
20 we have with regard to HIV positive inmates very much
21 parallel those in communities, but I think that you
22 also would need to take into consideration the type
23 of inmates that we have within federal prisons, and
24 that is that it would be important for the Commission
25 to examine what kind of prisoners are incarcerated

2 within federal prisons, for what offenses, versus
3 what kinds of individuals are incarcerated in state
4 prison.
5 For example, murder is not a federal
6 offense in and of itself. However, it is a state
7 offense, so a murderer would normally find his or her
8 way into a state's system, rather than normally into
9 a federal system.
10 COMMISSIONER DIAZ: Can an individual
11 select to go into a protected situation within a
12 federal prison? Yesterday we heard of some
13 incarcerated situations where a person who is
14 homosexual can be in some way protected from other
15 prisoners on self selection.
16 Is this a possibility?
17 DR. MORITSUGU: Yes, it is a possibility,
18 should such an individual request. I cannot think of
19 an instance during my tenure where we have had that
20 kind of request.
21 COMMISSIONER DIAZ: Do the federal prisons
22 have any kind of a special program for women in jails
23 that are pregnant in federal prisons?
24 DR. MORITSUGU: Yes, we do, and again,
25 that program is evolving as we have an increasing

20

1
2 number of inmates and an increasing absolute number
3 of females in prison. Up to this point, our policy
4 has been that those female inmates who are pregnant
5 are sent to our federal women's prison in Lexington,
6 Kentucky where we do have a hospital, where we do
7 have close ties with the University of Kentucky in
8 Lexington, where the females would get prenatal care,
9 would be able to deliver as well as the infant would
10 be able to be placed within that community.
11 Because of the increasing number of
12 inmates who are females, obviously the increasing
13 number of pregnancies, we are looking at establishing
14 two or three additional centers throughout the
15 country which may be closer to the inmate's home of
16 record, as well as looking at situations where in low
17 security inmates, we may consider perhaps a medical
18 furlough for a brief period of time immediately
19 prepartum, and immediately post partum, which
20 provides the mother an opportunity to bond with the
21 infant, if the mother elects to keep the infant.
22 COMMISSIONER DIAZ: You've painted such a
23 comprehensive picture of HIV care in the federal
24 system, I just want to know if just in maybe two
25 words you can state any limitations that the federal

2 system may have regarding HIV care.
3 DR. MORITSUGU: Well, thank you for that
4 opportunity, and I will be very, very quick about
5 that.
6 Obviously, one of the constraints that we
7 have is an image problem that I think is all
8 pervasive throughout the entire correctional systems,
9 whether they be state, local or federal, and because
10 of the image problem of health care within
11 correctional systems, recruitment of qualified and
12 sufficient numbers of health care providers continues
13 to be an ongoing problem, one which we have got to to
14 address up front, because while we may have all the
15 systems in place, if you don't have the human
16 resources to deliver those programs, the best laid
17 plans would simply go fallow.
18 We have been successful up to this point
19 in being able to maintain a sufficient number of
20 human resources, but I think that this is going to be
21 an increasing problem not only in the federal system,
22 but also in other correctional systems as well. I
23 think human resources is going to be a major problem
24 across the board.
25 COMMISSIONER DIAZ: Thank you.

2 DR. DesJARLAIS: Clearly, the potential
3 for HIV transmission in prisons, federal as well as
4 state, is a critical problem for the epidemiology of
5 the disease and policy making.
6 At present, according to the data Ken had,
7 the data you talked about, transmission appears to be
8 very, very low. Do you have an explanation for why
9 it appears to be so low? Is it the low level of risk
10 behavior, the difficulty in transmitting the virus,
11 that people are using condoms and clean needles?
12 Why does it appear to be so very, very low
13 that even the documented cases that have been found
14 may have been infected before they came in?
15 It's clearly going to have very big policy
16 implications to understand what's going on.
17 What is your current best understanding?
18 DR. MORITSUGU: I really do not mean to
19 sound flip when I provide you with a short answer,
20 but we would hope that this indicates that our
21 intensive education program and the application of
22 universal precautions across the board is working. I
23 think for any of us, as some of the previous
24 witnesses have stated, to believe that high risk
25 behavior does not go on within any correctional

2 setting is playing ostrich, that we put our heads in
3 the sand, and I think it's a given that in any group
4 of individuals, some level of high risk behavior may
5 very well be occurring.
6 We in the federal prison systems do not
7 provide condoms. We do not provide needle exchanges,
8 and that has been a policy that has been very, very
9 carefully thought through based upon what our
10 balancing options are.
11 On one hand, in the ideal situation, if
12 one were to be all public health oriented, one would
13 say let us do everything we can do along these lines.
14 On the other hand, the balance is that we have a
15 legal fiduciary and to do such a thing would be
16 contrary to that fiduciary.
17 We believe that by having an intensive
18 education program we have been able to balance off
19 the public health imperatives as well as the legal
20 imperatives. I would hope that our education program
21 is the cause for not seeing a higher level of
22 transmission within the federal prison system, and
23 that is basically what I can explain and the only way
24 that I can really explain it to you.
25 Otherwise, we would be seeing a higher

2 rate of seroconversion because we have been following
3 those cohorts for upwards of three years now, and we
4 havè not really observed that high level of
5 seroconversion.
6 DR. OSBORNE: I think we need to go on.
7 Harlon, you had a technical point.
8 COMMISSIONER DALTON: Less of a technical
9 point. Dr. Moritsugu, you said that--I'd like to
10 continue this conversation, and if I were to direct
11 some questions to you, would you be good enough to
12 answer them for the record, and if I were to call you
13 for a more informal conversation, you would answer my
14 telephone call?
15 DR. MORITSUGU: I most certainly would.
16 We are very, very much--we are very proud of what we
17 believe we have in place and I certainly am not
18 ashamed to discuss or to answer any questions that
19 you might have.
20 COMMISSIONER DALTON: Would you please,
21 Karen Porter is sitting behind you, and would you
22 make sure she knows how to reach you?
23 DR. MORITSUGU: She knows how to reach me.
24 DR. OSBORNE: Thank you very much for your
25 testimony.

2 We'll next have a panel discussing issues
3 in correctional state experiences; Alexa Freeman from
4 Alabama; German Maisonet from California, Catherine
5 Hanssens from New Jersey and Michael Wiseman from New
6 York.
7 If all of you could join us, we'll
8 appreciate it.
9 Let me ask you to introduce yourselves as
10 you speak, since I think I also mispronounced some
11 names. If you could keep your comments just as brief
12 as you can relating to written testimony, which will
13 be easy to see and study, that gives us the maximum
14 opportunity to interact with you, so we'll have a
15 little timer that will remind you when you have about
16 one minute left.
17 Thank you very much and proceed.
18 MS. FREEMAN: Dr. Osborne, my name is
19 Alexa Freeman, I am lead counsel in Alabama, but I am
20 happily not from that state, given my experience down
21 there.
22 DR. OSBORNE: Thank you for that point of
23 clarification.
24 MS. FREEMAN: I also want to say
25 parenthetically, not on the point of AIDS, that I

2 work with the National Prison Project, and I don't
3 think that the picture that Dr. Moritsugu has painted
4 about the Federal Bureau of Prisons is as rosy as he
5 would have you believe, and I would refer the
6 Commission to a series of articles that were written
7 by the Dallas Morning Star last year that I think are
8 very critical.

9 DR. OSBORNE: We actually have those in
10 our briefing packet for this meeting.

11 MS. FREEMAN: My testimony today, however,
12 will focus on the AIDS policies and practices of the
13 Alabama Department of Corrections and the ongoing
14 litigation that are challenging those policies in the
15 case of Harris v. Thigpen.

16 I first became involved in Alabama when I
17 received a phone call from the Alabama Prison Project
18 in 1987 asking for advice on what to look for during
19 a tour that they were making of the state's two HIV
20 units for prisoners and after I described for them
21 what I thought ideal corrections response should be
22 and what they were looking for, I asked them to get
23 back to me with their findings.

24 They called me about a month later with a
25 very chilling report. As a result, I then went down

2 to Alabama to investigate for myself. Let me
3 describe for you what we found.
4 Prisoners were being tested for HIV
5 antibodies without any idea this was being done to
6 them. No pre or post test counseling was provided.
7 A prisoner testing positive typically learned of this
8 fact from a masked and gloved correctional officer
9 coming to escort the prisoner from school or work to
10 an isolation cell.
11 As Dr. Cohen recounted, several prisoners
12 told us how officers had told them they had "the
13 fucking AIDS." Others were told absolutely nothing.
14 They stayed in isolation for days, weeks and
15 sometimes for months awaiting transfer to the two
16 special HIV units in the system. During this time,
17 they received little or no counseling about their
18 test results. Most of the information they received
19 came from correctional officers or each other and it
20 was frequently wrong. Some were told they only had
21 days to live.
22 They suffered immense anguish, thinking
23 that death was imminent, yet they were denied visits
24 with the chaplain or with mental health staff. Their
25 ignorance and fears were compounded by the

2 Department's practices of requiring them to wear
3 masks and gloves and in some instances rubber
4 clothing or even Saran Wrap around their bodies and
5 rubber footwear. They had to eat on disposable
6 plates and use plastic utensils. Some of them were
7 required to scrub the telephones with alcohol after
8 each use.
9 Their clothing and laundry bags were
10 stamped with the word "HIV." Even their trash bags,
11 which were bright red, singled them out. One
12 prisoner was required to scrub the shower stall and
13 toilet seats with pure bleach every time he used
14 them, and then to mop the floor with this bleach
15 behind him as he walked back to his cell. They were
16 let out of their isolation cells only for an
17 occasional shower and phone call. They had no
18 visits, no chapel, no recreation and no program.
19 Their only human contact was shouting with each other
20 through the walls.
21 After they were transferred to the
22 permanent HIV units, they fared little better. Women
23 were housed in a special unit at the Tutweiler Prison
24 for Women, and men were sent to the Limestone
25 Correctional Facility, which is on the Tennessee

2 border many miles from their families. They lived
3 locked away from the rest of the general non-HIV
4 population. They had no school, no recreation and no
5 work and they had no access to the law library. The
6 entire prison knew that they had tested HIV positive
7 because of their segregated status, and outside
8 visitors were warned before they came to visit that
9 the prisoners they were coming to visit had AIDS and
10 the parole board was notified of each prisoner's HIV
11 positive status.

12 I think that one of the most tragic
13 aspects of this litany of horrors was the prison
14 system's callous disregard for their medical needs.
15 The contract medical providers assumed that HIV
16 disease was completely untreatable. They were given
17 Tylenol for their pain and ignored entirely until the
18 verge of death.

19 Contrary to what they say, AZT was not
20 provided to prisoners until they were almost dead and
21 they never took T cell counts. The responsible
22 physicians during deposition admitted that they had
23 not heard of aerosolized Pentamidine. Our medical
24 experts, including Dr. Cohen who testified here
25 earlier, said that every single case of AIDS and

2 symptomatic HIV disease was mishandled, every one.
3 Several prisoners died as a result and countless
4 others suffered unnecessarily.
5 On the other side of the fence, the
6 apparently uninfected populations at Tutwiler and
7 Limestone were given no education about the disease.
8 Many were terrified of living on the same grounds
9 with the HIV positive population. AIDS panic gripped
10 the prisons. I should say it also gripped the
11 community in which they were located, Capshaw,
12 Alabama where Limestone was located, the community
13 was afraid to have their sewage mingled with the
14 sewage from the prison because they thought that
15 mosquitos would then breed on the sewage and then
16 infect the entire town.
17 At the same time, prisoners remained
18 ignorant of the means by which they could get
19 infected. Many of those who had tested negative one
20 time on intake thought that as a result they could
21 not possibly be infected nor could they ever become
22 infected in the future.
23 I want to point out two other appalling
24 aspects of their program: One is that we had very
25 serious concerns about the testing quality that was

2 conducted by the contract medical provider. The
3 laboratory technician admitted that she had no idea
4 how to conduct a Western Blot and she would often
5 call the Public Health Department in the middle of
6 conducting the test for instruction and we later put
7 on evidence at trial of several cases of misread
8 Western Blot results.
9 Secondly, the HIV positive prisoners in
10 Alabama spent on an average more time in prison than
11 HIV negative prisoners and that is because they are
12 not eligible for community release and also because
13 the parole board was notified of their HIV status,
14 even though there was not an official policy that
15 would deny HIV positive prisoners the opportunity to
16 be paroled, they're often not able to get paroled
17 because potential job or home placements turn them
18 down because of their HIV positive status, so they
19 tended to serve their entire sentences in quarantine.
20 During the course of the litigation in
21 Harris v. Thigpen, many of the conditions I have
22 described did change and improve, and I am convinced
23 that this is due to the lawsuit. However, the
24 Department has clung obstinately to its policies of
25 segregation and testing, mass testing.

2 The case went to trial in the spring and
3 summer of 1989. We challenged the testing and
4 segregation program; the failure of the Department to
5 provide adequate education and testing and
6 counseling, the grossly inadequate medical and mental
7 health care and the denial of law library and
8 programming to segregated prisoners. We brought it
9 as a class action on behalf of all Alabama prisoners
10 because our view was that it was not only those who
11 tested positive who were affected by these policies,
12 but all prisoners were subjected to the mass testing,
13 all prisoners were harmed by the failure to provide
14 adequate education and we were convinced because of
15 the testing error potential that a number of the
16 prisoners who were in the apparently HIV negative
17 population were probably infected, and in more cases
18 likely to transmit the disease than those who were
19 segregated.
20 I have in my testimony, because I realize
21 I've run out of time, a summary of some of the
22 reasons why we are quite optimistic that we will
23 obtain a reversal in the 11th Circuit. The trial
24 judge in our case found for the defendants on every
25 single count, but we also think he made a number of

2 legal errors and really made no findings of fact, so
3 we are optimistic that we will prevail.
4 I have provided for you all a copy of our
5 trial brief which summarizes better than I could
6 today the facts of our case. Also an article from
7 U.S. News and World Report which describes for you
8 the quarantine units in Alabama and a copy of the
9 trial court's opinion which I think you'll be apalled
10 to read.
11 Thank you.
12 DR. OSBORNE: Thank you very much for your
13 very important work. I think if I could ask
14 everybody to give their testimony initially, then
15 we'll have a chance to interact afterwards.
16 DR. MAISONET: My name is German Maisonet,
17 I am the chief of HIV services for the California
18 Medical Facilities Department of Corrections of the
19 State of California. I am a transplanted New Yorker,
20 and I'm educated and raised here in New York City. I
21 did not go to medical school to take care of AIDS.
22 I'm a pediatrician and pediatric oncologist by
23 training. I was very involved in child abuse and
24 later found a link between child abuse and drug
25 abuse.

2 I volunteered to become the medical
3 director of a recovery home in my neighborhood, which
4 became the largest and most respected recovery home
5 for gay and lesbian alcoholics.
6 In 1980 and '81 the nightmare began.
7 Briefly, the California Department of Corrections has
8 approximately anywhere from 60 to 85,000 persons
9 enrolled in the CDC system, and when we use CDC, we
10 mean California Department of Corrections, small CDC.
11 They are in the following status; either inmates or
12 parolees, and as inmates they're either in prison
13 camps, prison itself, honor camps or they may be in a
14 California Youth Authority or they may be inmate
15 patients at one of the three major medical
16 facilities, Chino Institution for Men, California
17 Men's Colony, California Medical Facility and there
18 are two to three women's prisons, the largest being
19 Fontana Institution for Women. California Medical
20 Facility is the largest prison hospital in the state.
21 HIV testing is voluntary at our
22 institutions. The only situation in which there can
23 be mandatory testing of an inmate is during a staff
24 assault, if there is any thought that there might
25 have been transmission of any contaminated body

2 fluids which could act as a contagant.

3 Seroprevalence in prisons in 1987 to 1988,

4 three to five percent our inmates arriving at the

5 Northern Reception Center at the California medical

6 facility tested positive in a blind survey. However,

7 this survey is flawed, since the bloods drawn were

8 drawn through venous puncture, arterial punctures,

9 especially since addicts who had a longer time using

10 drugs, who had collapsed their veins were more likely

11 to be involved in high risk behavior for a longer

12 period of time were excluded. Therefore, it's not

13 surprising that when I reviewed some of the data from

14 inmates voluntarily testing at the California Medical

15 Facility, Northern Medical Reception Center, inmates

16 stayed there for approximately three months,

17 California Medical Facility is where they are

18 sentenced after they've been back to prison and the

19 State can be anywhere from nine months to as long as

20 life, I found reviewing it for the past 13 months

21 seroprevalence of eleven percent.

22 Which is a very sad tale and that is the

23 longer our inmates stay in jail the longer they're

24 likely to be infected, and so people are being

25 infected in jail. It's a myth that they all come in

infected. Many of them are being infected in jail. However, I cannot explain one phenomena and that is there's a much lower rate of sexually transmitted diseases amongst these inmates who when they leave the prisons, especially if they're heterosexual and more likely to participate in the epidemic of syphilis, gonorrhea and chlamydia. I have not been able to completely decipher this.

Housing: Once an inmate tests positive, their segregated. In our facility they're either in what we call L1 or N1 wing, and they're closed to the general population. Several years ago, due to the lack of participation in the other programs allowed to general population inmates, our inmates sued in the now famous Gates versus Majon case, and a pilot program was established for a select group of inmates who are HIV program who are allowed to participate in a general program, they're all housed together. This had a positive effect.

The number of inmates who are testing voluntarily in our prison has jumped from 40 per month to approximately 100 or 120 per month. Seroprevalence rate is still the same. It's recently dropped slightly. That's because we believe we've

2 gotten most of the individuals who are willing to
3 test.
4 In addition to the modes of transmission
5 which are cited outside of prison, one must remember
6 that a major mode of transmission is tatooing in
7 prison.
8 There are several things that we do, and
9 I'd like to tell you about those briefly, and then
10 I'd like to tell you about the deficits in our
11 system, which are many.
12 At this point, we have an HIV service.
13 Please don't think that this is a huge service with
14 many, many people. There are exactly two of us who
15 are full-time there. We have 8,000 inmates, and
16 we're responsible for all HIV care to approximately
17 250 inmates, rapidly growing. The number of inmates
18 that we get positive per week is about one to two new
19 inmates from our own institution per week, not to
20 mention as many as ten transfers per week from other
21 institutions.
22 Since we have the physicians who have more
23 experience, we get approximately ten transmissions.
24 At this point we are the HIV oncology center and we
25 tend to take all inmates with T cell counts less than

2 200.

3 The fallacies and some of the deficits

4 that we have: First of all, there is no medical, any

5 medical or rational or scientific basis for the

6 segregation of inmates who are HIV positive. In

7 fact, it creates a myth, and that is they are locked

8 up there, I do not have to watch out. The number of

9 custodial staff and professional staff who

10 participate in what I would call less than adequate

11 protection of themselves, I think increases when

12 inmates are allowed to--when they're segregated.

13 Second thing is the inmates themselves

14 believe that they are now safe.

15 My greatest problem at this point is not

16 my HIV positive inmates. My greatest problem now is

17 having putatively heterosexual men continually

18 solicit sexual favors from our effeminate male

19 homosexuals. California Medical Facility is also a

20 facility that houses most of the men convicted of

21 rape or sexual crimes in the State of California.

22 So housing has created this myth

23 that--segregated housing has created in myth that we

24 don't have to worry about HIV in the general

25 population. Obviously, with a seroprevalence rate of

2 3 to 5 percent out of 8,000 inmates, you can quickly
3 come up with the fact that most inmates who are HIV
4 positive have not been identified and are still
5 involving themselves in either high risk behavior in
6 either one form or another and infecting themselves
7 and others.
8 The problem becomes greater because
9 although prisons seem to, because we want to lock
10 them up and put them in jail, seem to portray or
11 represent, project this image of a responsible into
12 society, we are not, we are not being responsible.
13 First of all, we don't give our inmates any condoms.
14 As a physician I am limited as to the words that I
15 can use, and I can tell you publicly that I do not
16 follow those guidelines and restrictions placed on me
17 by the state. And I don't intend to, because I am a
18 physician and I answer to a law that seems to be a
19 little higher than any law that the courts can.
20 I think something really happens to
21 society, which is very sad, when physicians feel they
22 have to answer to custody. I think it's very sad. I
23 don't think we have to look much beyond Germany to
24 see what happens.
25 Conjugal visits: Our inmates are not

2 allowed conjugal visits because they're HIV positive.
3 Now let's review that. And the reason for that is
4 we're going to bring an HIV infected child into this
5 world. Well, obviously, most inmates are not, who
6 are HIV positive are not identified. We don't
7 provide condoms there, so I see a little bit of a
8 dichotomy and I believe that it's basically, that
9 it's not okay for people who are HIV positive to be
10 sexual, if they're identified. So what we're saying
11 is if you're HIV positive, we will take away and you
12 volunteer and you allow us to follow you, then you
13 will take your rights away.
14 The second is there is no psychotherapy
15 available in any adequate amount for our inmates.
16 There's no proactive planning, we still do not have a
17 five year plan with California Department of
18 Corrections.
19 Overcrowding: It's very frightening the
20 amount of tuberculosis in our institution is going up
21 very rapidly. There is a rule of thumb we tried to
22 teach all our physicians. If PPD reactive, you are
23 HIV positive until proven otherwise in our
24 institution. This has been lost on our physicians,
25 who are very glad to see an HIV team, and we keep on

5

2 telling them you are taking care of most of the HIV
3 positive inmates, not us, but they still do not wish
4 to take care of many of our inmates.
5 A major problem that we now face is
6 hospice care. Most of our inmates are going to die
7 in our institutions and we have no place to place
8 them. Some of our inmates, and I've have to do this,
9 I've had to revoke their parole and call their
10 lawyers and say I'd rather have them die in jail than
11 die in the street. I think there is a dignity of
12 life which even a prison should not take away from a
13 person once they are sick.
14 Societal deficits: First of all, it's
15 very sad to say that most of our inmates, especially
16 men of color, and poor white men are men of color,
17 get better medical care in prison than they do when
18 they're free men. So we reward people with better
19 medical care when they commit crimes than when they
20 try to lead complete decent lives. In other words,
21 when our inmates are paroled they have worse care
22 when they're free men. This would account for the
23 recidivism rate of approximately 90 to 95 percent
24 amongst our HIV positive men who are identified.
25 They come back to jail because they get better

2 medical care from us. We must remember that MediCal
3 and Medicare will not pick up these inmates.
4 Two, there's a double message we're giving
5 these inmates. We ask them to--we're basically
6 teaching people outside of prison how to continue at
7 some times to involve themselves, quote, in high risk
8 behavior in doing it safely. You must understand
9 that most of my inmates get into jail because they
10 were involved in high risk behavior. They're either
11 involved in sexual activity or they were involved in
12 drugs, and there's a myth that the alcohol, which is
13 the drug of choice amongst most of our inmates, if
14 you do not believe that, they can process as many as
15 75 gallons of alcohol in a weekend, we have removed
16 that many from our locked units, they do it with
17 their fruits or vegetables, or whatever. They can
18 get alcohol in, I don't know how they do it, but they
19 do it. Life is tedious but never dull in the state
20 prisons.
21 The other thing, and this is one I think
22 I'm really very bothered by, and that is that most of
23 my inmates, I would say 90 percent of my guys have
24 been victims of childhood molestation or rape.
25 Prison is not a place for people who have undergone

2 that, hospitals are, and we're locking up the victims
3 and it seems that the perpetrators are getting away.
4 I can assure you, of all my inmates, 90
5 percent of them have been victims of molestation but
6 only one to two percent have ever been perpetrators.
7 I think there's something going on, I think we have
8 to look at that. HIV is pointing up some very
9 glaring discrepancies and very sad things we are not
10 doing.
11 There are six things I would like the
12 Commission to remember, if I had to.
13 First, the virus is not impressed, it
14 doesn't matter who or what you are, what you think or
15 what you believe. It's what you do and it's
16 obviously not impressed with the correctional
17 facilities, because we're not doing a good job.
18 One of the things I would like to point
19 out is that the reason that we have a higher rate in
20 the state prisons as opposed to the federal prisons,
21 is not that we're doing a worse job, it's that most
22 high risk behavior is a felony. It's not a federal
23 crime. That's why we have a higher seroprevalence
24 rate.
25 Prison is not adequate treatment for

2 people who are alcoholics and drug addicts and we
3 basically say that people who do not have access to
4 third party payment deserve to be treated in prison.
5 I'm not there to treat alcohol and drug addiction
6 necessarily, but that's what most of my inmates are
7 there for.
8 The achilles heel. We have an epidemic,
9 which basically is transmitted sexually or through IV
10 drug use, and if you ask most physicians what two
11 disorders they're taught least about in medical
12 school, it's sexually transmitted diseases, and in
13 addition drug and alcohol abuse, and the patients
14 they least like to treat are people who are not
15 compliant with their treatment, are not reliable
16 historians, cannot pay their bills and do not keep
17 their appointments. That is the profile of most
18 inmates in jail, that's why we can't get adequate
19 treatment for them.
20 None of my inmates, and I would like to
21 say this and it is a political statement, but I have
22 to say it. None of my inmates have a pilot's
23 license, none of my inmates are bringing the drugs
24 into jail. It's either the doctors, the custodial
25 officers or some of their relatives who are coming

2 in. That's how drugs get into jail.

3 Five, diabetic IVB users have a markedly

4 lower rate of HIV infection, markedly. If you look

5 at IVB users, you might also find that needle

6 distribution does work.

7 Six, Medicare and Cal will treat the

8 complications of drug abuse and HIV, but they will

9 not in any way, shape or form recognize chemical

10 dependency. Therefore, society is going to wait

11 until the patient gets sick. Therefore, we make

12 money from keeping people sick and treating their

13 illness than preventing illness. I think the inmates

14 understand that, and last, but not least, medical

15 care is a privilege in this country, it is not a

16 right, and if that is true, then those people who are

17 not privileged, basically the poor blacks, Latinos,

18 Asians, prostitute IV drug users and gay men and

19 women have the right to poor medical care.

20 Thank you.

21 DR. OSBORNE: Thank you very much. I'm

22 tempted to say that New York State's loss was

23 California's gain. I'm absolutely tempted to say

24 that pediatric's loss is internal medicine's gain.

25 As a fellow pediatrician, we used to protest that

2 children are not just small adults, but I think
3 you're beginning to demonstrate that adults are just
4 large children.
5 MS. HANSSENS: I'm Catherine Hanssens, I'm
6 a staff attorney with an agency called the Department
7 of the Public Advocate, which is a statutorily
8 created agency with the mandate to represent the
9 public interest, and even in our own agency we don't
10 always agree what that is.
11 There's a subdivision of the public
12 advocate, the Office of Inmate Advocacy, which is
13 where I work. Part of my work has involved
14 representation of inmates on AIDS-related issues, and
15 I'm basically the Department's AIDS person, for
16 whatever that's worth.
17 I brought a corrected copy of my
18 testimony, if that's of interest to anybody, so I can
19 provide a copy to the stenographer if you like.
20 The conditions under which incarcerated
21 people in New Jersey are confined varies with the
22 system and the institution. The State Department of
23 Corrections does not test everyone on admission, but
24 they do automatically segregate everyone who advances
25 to a diagnosis of AIDS. They are segregated in

2 what's called the special medical unit.
3 Unfortunately, contrary to the suggestion implicit in
4 the name, the SMU is not an infirmary, but an
5 involuntary administration housing area, and there
6 are two in the state. There's one in Clinton for
7 women, there is one in the maximum security prison in
8 Trenton.
9 Regardless of prisoners' classification
10 status, before their AIDS diagnosis or the level of
11 their health after they recover from the
12 opportunistic infection which triggers their
13 diagnosis, these prisoners remain isolated as maximum
14 security prisoners, barred from participation in
15 programs and facilities available even to other
16 maximum security prisoners. All of these prisoners,
17 including those entering the unit with minimum
18 security status, are ineligible for work release or
19 furloughs, regardless of whether they had
20 successfully participated in such programs prior to
21 crossing the magic line to AIDS. In fact, contact
22 with other prisoners is prohibited for these people.
23 In the State prison system, AIDS is a
24 great equalizer, and a prisoner's AIDS diagnosis
25 substitutes for any other classification system based

2 on offense, prior record and the like, which governs
3 all other prisoners in the system. In fact, there is
4 only one other group of prisoners in the State prison
5 system in New Jersey who are subject to automatic
6 segregation without periodic review, and those are
7 inmates under sentence of death.
8 In county correctional facilities policies
9 on housing of prisoners really vary by county. Some
10 segregate only those who are symptomatic, some
11 segregate those for whom there is evidence of
12 seropositivity or just the suspicion of
13 seropositivity, and in a lot of institutions
14 outwardly gay inmates are automatically segregated
15 for fear they may be carrying the HIV virus.
16 Recreation and visitation opportunities for those
17 persons are invariably restricted and the segregation
18 of these inmates effectively announces their medical
19 status to security staff and to the rest of the
20 inmate population.
21 Until late 1988, AZT was available in the
22 state system only to the relatively small percentage
23 of prisoners with HIV disease who were segregated in
24 the SMU or the special medical unit. State prison
25 officials have, since the filing of a lawsuit by our

2 office, have expanded distribution of AZT to other
3 medically appropriate recipients. However,
4 distribution of AZT and other prophylactic measures
5 in the State system still do not conform to protocol
6 which the Centers for Disease Control and our own
7 Department of Health have recommended and I
8 continually receive reports of chronic delays in the
9 diagnosis and treatment of persons with HIV disease.
10 The diagnosis and treatment of
11 seropositive individuals in county jails is even more
12 unpredictable. I've had a number of experiences
13 where inmates entering a county facility with a
14 prescription for AZT were not able to get the
15 continuation of the drug until our office intervened.
16 Independent medical assessments of county
17 jail inmates for treatment with AZT and Pentamidine
18 is the exception rather than the rule, and I think
19 it's that kind of situation that indicates that the
20 jail officials' zeal for identifying and segregating
21 seropositive inmates often has absolutely no
22 connection to a regiment for monitoring or treating
23 these inmates.
24 The major issues affecting treatment for
25 prisoners in New Jersey with HIV are in part a

2 product of the confusion, conflict and fear which
3 underlies much of the public discussion of AIDS. The
4 burden borne by prisoners with AIDS, I think is
5 magnified by the general public hostility towards
6 criminal offenders, even those who are detained for
7 suspicion of a crime, and the perception that these
8 people once incarcerated have no rights. The
9 perception is reflected in the quality of medical
10 care that I see in state and county facilities, and
11 the lack of concern for the related needs of the ill.
12 Prison officials and even medical staff
13 often treat a prisoner's diagnosis of AIDS as further
14 evidence of wrongdoing, and the combination of
15 ignorance and hostility has literally been deadly for
16 a lot of prisoners in New Jersey.
17 One of the most disturbing manifestations
18 of that type of hostility and ignorance which
19 prisoners with AIDS must deal, I think is illustrated
20 through the attempted murder conviction of a New
21 Jersey prisoner who was accused of biting a
22 corrections officer a little earlier this year.
23 Despite conflicting evidence and total lack of
24 evidence at the hearing that the virus had ever been
25 transmitted through biting, the inmate received a 25

2 year conviction. At the time of his conviction he
3 was within months of parole eligibility for a
4 burglary conviction for which he was previously
5 convicted. He must now serve an additional 12-1/2
6 years before he could be eligible for parole.
7 The only witnesses to the assault were the
8 correction officers who claim to have been assaulted,
9 by the handcuffed inmate, who claimed he was the one
10 assaulted at the time.
11 The court in my view really recommended a
12 death sentence as punishment for the inmate's
13 illness.
14 This is particularly of concern to persons
15 working in the corrections system who know that
16 frequently excessive force against inmates is
17 accompanied by the launching of assault charges
18 against the victim to cover the assault.
19 I'll try to briefly summarize the areas of
20 primary concern. These are based on my
21 representation of inmates and requests that I get for
22 assistance, and I think they are the primary issues
23 of concern to prisoners in New Jersey.
24 Segregation and isolation is a primary
25 one. With very few exceptions, the prisoners whom I

2 have represented identify permanent isolation from
3 the rest of the prison as a major aggregate in coping
4 with their illness.
5 Medical treatment is also a primary
6 concern. Prison and jail inmates actually have a
7 more clearly defined right to medical care than do
8 free citizens. There are a number of court cases on
9 that issue and there are also a number of court cases
10 that say that the cost of needed treatment will never
11 justify its total denial. Regardless, even those
12 persons segregated in what's called the special
13 medical unit continue to provide instances of weeks
14 in delays to responses to extreme medical physical
15 discomfort, missed medications, incorrect medications
16 and lack of response when there are medical
17 emergencies, and as a result, inmates segregated in
18 this unit really live under the perpetual fear that
19 when they are in medical crisis, there will be no one
20 there to respond.
21 Confidentiality and discrimination is
22 another primary concern. It is a prisoner's right to
23 privacy really, in terms of the bodily integrity
24 brand of privacy is the same as any free citizens'
25 and unfortunately the State Department of Corrections

2 does not agree and routinely, even though there is
3 this official policy of confidentiality, routinely
4 releases information about seropositivity without
5 releases and without a court order, even to outside
6 law enforcement officials. The consequences of the
7 release of that information are devastating, both to
8 inmates who are facing parole, and to inmates within
9 the system.
10 Education and counseling is another
11 serious problem in the state and county correctional
12 facilities. The State Health Department does provide
13 education and training in the state and county
14 system, but they have two people statewide to provide
15 training and education to correctional facilities,
16 police departments and emergency response personnel.
17 It's obviously inadequate. They estimate
18 they reach about 4,000 prisoners a year. That's
19 about 13 percent of the 31,000 who are in the system
20 on any particular day, so it's barely scratching the
21 surface.
22 The continued incarceration of people with
23 end stage AIDS under maximum security conditions
24 really serves no conceivable penological purpose, but
25 there's no readily available mechanism in New Jersey

8

2 for the release of inmates who are terminally ill,
3 and in fact, there is a medical clemency procedure in
4 New Jersey, but the process is so prolonged and the
5 criteria are so stringent that those who meet the
6 criteria often are dead before their application gets
7 to the Governor's desk.
8 DR. ROGERS: Ms. Hannsens, I'll have to
9 ask you to close rapidly, to my sorrow. We do have
10 your testimony.
11 MS. HANNSENS: The only other thing of
12 primary concern is a dearth of persons on the
13 outside, lawyers or otherwise, available and familiar
14 with the corrections system to provide
15 representation. It is virtually impossible for most
16 of these persons in prison to resolve their medical
17 and other problems within the prison system without
18 outside assistance, and that's a particular problem
19 in New Jersey.
20 Thank you.
21 DR. ROGERS: Thank you.
22 DR. OSBORNE: Thank you very much. Mr.
23 Wiseman?
24 MR. WISEMAN: I'm Michael Wiseman, working
25 with the Prisoners Rights Project of the Legal Aid

2 Society of New York. This is my colleague Bill Roll,
3 he'll be happy to field some of your questions as
4 well.
5 It's almost a torturous process to ask a
6 lawyer to be concise and list in ten minutes the
7 major problems in a state system like New York.
8 Since I couldn't possibly do that--
9 DR. ROGERS: Let me just respond and say
10 this is eloquent testimony, it's very powerful, we
11 hate to cut any of you off.
12 MR. WISEMAN: In the expectation perhaps
13 of being cut off, I compiled some exhibits which I
14 didn't get to Miss Porter in time to have massively
15 reproduced. I had ten of them with me, they're all
16 gone, I'll have this copy with me, and I'll be
17 referring to some things in there.
18 We have brought suit against the State of
19 New York on a statewide basis under the lawsuit
20 captioned "Inmates of New York State with HIV
21 Infection versus Cuomo and Other Defendants." That
22 complaint is contained in these exhibits, and it sets
23 forth in much more detail our view of what the major
24 problems are.
25 I'm going to be happy to depart from my

2 prepared testimony and try to import to you a sense
3 of the urgency facing New York State, and I imagine
4 many other states, as well as respond to some of the
5 issues that have been brought up so far this morning.
6 If I could use one word to describe the
7 present state of affairs in New York State,
8 "cataclysmic" comes to mind. If I thought of another
9 word, "disastrous" would certainly come to mind and
10 "emergency." Obviously, the whole AIDS epidemic can
11 be categorized in that way, but we have an emergency
12 within an emergency.
13 New York State has approximately 55,000
14 people incarcerated in about 60 facilities.
15 Estimates are about 20 percent are seropositive and
16 at any given time approximately 1,000 of those people
17 are actually symptomatic. Statistics are that people
18 in New York State prison who are HIV infected live
19 one-third as long as people in the community, even
20 accounting for demographics.
21 An IV drug user in a New York State prison
22 can expect to live one-third as long as a drug user
23 in the streets of Manhattan. As of two years ago,
24 about 28 percent of people who were autopsied were
25 identified as being HIV infected for the very first

2 time at autopsy. That's a shocking statistic.

3 In the city jails, the situation is almost
4 as bleak. Approximately 7,000 of the people who pass
5 through New York City jails a year are HIV infected,
6 and it is also the leading cause of death in New York
7 City jails.

8 Nothing in my professional training nor in
9 my life experience prepared me for this case that
10 I've been working on for the last two years, going
11 from prison to prison, interviewing ill and dying men
12 and women who had no hope of early release, who were
13 housed hundreds of miles and nine, ten hours from
14 their families, who were receiving minimal, if any
15 medical attention, and who are asking for help. It
16 was truly one of the most remarkable experiences of
17 my life.

18 Getting back to my office the next week
19 and getting anguished phone calls from their family
20 members, thinking at last help was on the way, only
21 to have me tell them, "I'm sorry, there's very little
22 we can do, there is no early release, we can't make
23 them do more in an individual case than what they're
24 doing," just hightened the sense of anguish that I
25 and my colleagues felt.

2 What this committee can do to address this
3 in a broad sense, this catastrophe going on in the
4 State of New York, and just in response to Miss
5 Freeman's comments, this is New York State, this
6 isn't Alabama, some would think we're supposed to be
7 more enlightened, experience would dictate that's not
8 the case. I don't think it's a geographic
9 distinction here. What needs to be done is the
10 Government, the federal Government has to recognize
11 the situation in New York State as a particularly
12 intense disaster, much like the federal government
13 moves in and provides disaster relief for other
14 natural phenomena like hurricanes and earthquakes,
15 that type of view has to be taken.
16 Federal legislation recently passed
17 allocated certain money to the State of New York and
18 the City of New York. I'm not certain as I sit here
19 today if that money is earmarked for Corrections. My
20 guess is it's going to be split up among various
21 competing groups. That certainly is not adequate.
22 It's a step in the right direction, but not adequate.
23 Massive amounts of money must be allocated solely for
24 the treatment of AIDS, HIV infection in Corrections.
25 That is at the root of some of the or most of the

2 other smaller issues that I could address, such as
3 lack of acute hospital beds, lack of qualified
4 providers, lack of adequate education and testing.
5 Just to respond to a couple of the points.
6 I'm a little disturbed hearing people make the
7 comparison that, well, prisoners get better health
8 care than people on the street. I really don't think
9 that's an issue in any of this discussion, nor should
10 it be. I like to think about that the tide will rise
11 and bring up all the ships.
12 Fortunately, prisoners do have at least
13 the right on paper to adequate health care. If that
14 right were enforced, I think the compassion and the
15 knowledge learned and generated from that endeavor
16 would hopefully help poor people in the community
17 also to get health care. I don't think the response
18 to that comparison is to say, well, let's not give
19 prisoners too good care because then they'll just
20 want to get back into jail to get care. I haven't
21 met anyone who feels that way in jail.
22 The Department of Correctional Services in
23 the State of New York is truly a growth industry.
24 Their budget this year was $1.2 billion and many of
25 the towns in upstate New York, Bear Hill, Danamora,

2 just to name a couple, primarily the only business
3 going on in town is corrections.
4 When you think about legalization, I think
5 you have to realize that you're up against the
6 reality that many people would lose their jobs if
7 those facilities close down and drugs were
8 decriminalized. I think you have to also look at the
9 reality if you took that $1.2 billion, and I've been
10 accused by many of the more particular conservative
11 factions in my own family of being a bleeding heart
12 in this issue, but it seems simple to me, if you took
13 the money you spent on corrections and took a portion
14 of that and put it back into the community for jobs,
15 education, not just drug education but real
16 education, you probably wouldn't have as many people
17 using drugs, you wouldn't have as many people going
18 to jail.
19 That may be oversimplified, but it always
20 seemed to me to make a lot of sense.
21 I just want to point out that in this
22 packet of exhibits, there is some description of the
23 treatment afforded for women prisoners at Bedford
24 Hills Correctional Facility, which our office has
25 been involved in litigation in. It was compiled by

2 the court, the court did not hear that case, and I
3 would like you to look at it in particular as the
4 kind of quote-unquote "care" people in the State of
5 New York are getting and the horrible shortfalls of
6 that care.
7 I also understand you saw the Fishkill
8 Correctional Facility special needs unit yesterday.
9 I included in my packet of information as well a
10 rather lengthy report from the New York State
11 Commission of Corrections which severely criticized
12 one of the other special needs units in New York
13 State which is located in the Sing Sing Correctional
14 Facility. There are a total of three such facilities
15 which have a whopping total of 36 beds to provide
16 care for the 10,000 HIV infected people that are
17 incarcerated, so I would urge you to look at that
18 report as well.
19 The last thing I want to comment on is the
20 notion that, or the debate as to whether
21 seroconversion is going on in our state correctional
22 facilities. Obviously, prisoners don't come forward
23 and volunteer information if they've been involved in
24 illicit activities within a jail. That's obviously a
25 limitation on any type of scientific analysis of the

10

2 situation. From anecdotal and other sources, we
3 estimate that approximately 30 percent of people in
4 state prison engage in either sex, tatooing or needle
5 use, other needle use. I dare say that if 30 percent
6 of the population is doing that type of activity in
7 one form or another, you can be certain, there's
8 really no debate in my mind, you can be certain
9 seroconversion is going on in state prison.
10 Did I do it in ten minutes?
11 DR. ROGERS: Very nice.
12 MR. WISEMAN: Thank you for the
13 opportunity.
14 DR. OSBORNE: Thank you for that set of
15 comments and I think that give us a few minutes.
16 We'll work in somewhat a revised schedule here and
17 try to interact until about 12:15 with the group that
18 just talked to us and then have the panel on women
19 and HIV infection before we break for lunch at about
20 12:45.
21 So we'll now have a few minutes with
22 Harlon.
23 COMMISSIONER DALTON: I have a few
24 questions for Mr. Wiseman and Dr. Maisonet.
25 First, a comment for Mr. Wiseman. I trust

2 you did not understand Dr. Maisonet in saying that
3 for many black men in this country they have much
4 better medical care inside than outside, that he
5 meant that to support lowering the quality of health
6 care in prisons. And I hope you don't assume that
7 anyone sitting at this table would draw that
8 conclusion, so I think you may have been just a
9 little too sensitive.
10 It seems to me that the meaning of that
11 statement is that we need to do something about the
12 general quality of health care in this country on the
13 outside, and it helps dramatically illustrate just
14 how poor the quality of health care is in many of our
15 communities, so I don't think anybody got confused
16 about that, so please sit back and relax.
17 Similarly I hope you don't mean to compare
18 New York to a state like Alabama. Alabama is a
19 special case off the charts, and I think it doesn't
20 help matters to try to make New York appear like
21 Alabama. You could still say all that you need to
22 say about the problems with incarceration for people
23 who are HIV positive here in New York.
24 My question to you, though, has to do with
25 your last comment about Fishkill being one of three

2 state prisons with special needs units with a total
3 of 36 beds for I guess 1000 symptomatic inmates. Are
4 you suggesting that--well, I guess my question is,
5 should the special needs unit be the only medical
6 care facilities for symptomatic inmates, or in your
7 vision should essentially all the health care
8 facilities within New York State be capable of
9 dealing with symptomatic HIV inmates?
10 MR. WISEMAN: In my prepared testimony I
11 cite a statistic that a study at New York City showed
12 17 percent of people leaving an acute hospital visit
13 or stay for HIV infection required a level of care
14 that's called in New York State skilled nursing care.
15 The 36 beds that exist right now in New York State
16 that are special needs beds in our view are nothing
17 more than segregated, HIV segregated infirmaries.
18 They don't provide a level of care that is necessary
19 for people who are just recently over an acute
20 episode and who need more than just infirmary care.
21 In other words, they need to have doctors
22 around them almost all the time or on call, they need
23 to have nurses around all the time, they need to have
24 specially trained personnel to recognize the
25 progression of their illness. That capacity in New

2 York, and there's no controversy on this, simply
3 doesn't exist.
4 The controversy, that is, there is no
5 controversy as to whether it exists, it simply
6 doesn't exist in New York. There are no skilled
7 nursing facilities in any of the correctional
8 facilities, nor do they have access to them in the
9 community, which means right off the bat 17 percent
10 don't get that level of care.
11 COMMISSIONER DALTON: Are you suggesting
12 that, and this may be putting words in your mouth,
13 but you may want to chew on them, are you suggesting
14 that all of the medical care facilities within New
15 York State institutions should be capable of treating
16 symptomatic patients, but that there's a need for
17 facilities that can treat people coming back into the
18 system from outside hospitals with quite acute needs
19 and that's a role that's supposed to be served by
20 this Fishkill unit that we saw and the other two
21 units, and it's not being served?
22 MR. WISEMAN: That's essentially right.
23 COMMISSIONER DALTON: My question for Dr.
24 Maisonet, you said many, many wonderful things. One
25 of the ones that I had difficulty figuring out how to

11

operationalize, you said that doctors ought not to answer to custody, that is to say--

DR. MAISONET: Yes.

COMMISSIONER DALTON: And you clearly do not, as you made quite plain, and I wish we could clone you, I think we can't. And in my experience, one of the real difficulties is there are a lot of dedicated doctors and nurses and physicians' assistants out there in prison systems around the country, but that ultimately the final authority on medical decisions as well as custodial decisions is custody, is the warden or even people below the warden, and how can we possibly get around that other than having ornery people like yourself?

DR. MAISONET: First, for Mr. Wiseman, I understand your concern, I think there are people in this country this would take what I would say and turn it around and try to lower the medical care.

MR. WISEMAN: I wasn't suggesting that.

DR. MAISONET: No, but I'm saying that.

I think it's not an easy position to be placed in, but from what I have seen at our facility is that when we talk about HIV care, we're not just talking about the inmates, we're also talking about

2 the custodial staff as well as the nursing staff,
3 because the custodial staff spends even more time
4 with the inmates than I do or the nursing staff does.
5 The first thing we did when we came in was
6 we saw our institution had no, quote, even the
7 foundation of an infection control committee or
8 employee occupational health service, and that's what
9 the HIV team served as, we served as a source of
10 information for them, so we weren't seen as being
11 antagonistic, we were seen as bringing the level of
12 medical care not only for the inmates but also for
13 the custodian staff up.
14 I don't know if we're different than a lot
15 of institutions, but we have found that there's a
16 group of officers that prefer to work on the HIV
17 unit, because they do become attached to some of the
18 inmates, and they themselves have served as a source
19 of information for other officers.
20 I think what happened is that as people
21 finally accepted the fact that HIV was a reality in
22 the prisons, there seemed to be more of a decrease in
23 the amount of tension, more of a taking on of
24 responsibility on the part of everybody including the
25 physicians, but I think the custody that you saw very

2 quickly, they needed information to protect
3 themselves and we took advantage of that and
4 exploited that and allowed us to establish a very
5 good working rapport with our custodial staff.
6 I don't go in there saying, "You're
7 custody, you're wrong, you're not at risk for HIV
8 infection, you're putting these guys down." That's
9 not the way I went in. "I'm a physician and you have
10 as much right to the information as the inmates do,
11 please utilize it. I'm going to take time," and that
12 seemed to work out nice.
13 COMMISSIONER DIAZ: Just very, very brief
14 questions which you might answer in one or two words.
15 I'm surprised at the high rate of
16 recidivism, and I'd like a comment on that, in your
17 prison system, and also I wonder if you can tell us
18 about the need for education of families and
19 communities who will receive these prisoners once
20 they've been out, and I think you've been the only
21 individual in our two-day visit here that's called to
22 our attention the possible drug connection between
23 staff and correction officers and the persons there,
24 and I'm surprised this has not come up, that this
25 country must confront, and I would appreciate getting

2 for the record, giving us your impression, having
3 served both coasts.
4 DR. MAISONET: We do not have a formal
5 program for continued outreach to the families, I
6 think it's something we have to look at. We are
7 obviously during conjugal visits having non-HIV
8 identified inmates having conjugal visits and
9 pregnancies are resulting from that where an HIV
10 child is being created.
11 As far as the drugs, it basically comes
12 down to who is not searched before you come down to
13 prison. It basically boils down to doctors, nurses
14 and custodial officers. Cocaine cannot be fermented
15 like alcohol, it has to come from somewhere. It
16 doesn't come from little birds and the stork doesn't
17 bring it, so somebody's got to bring it, and
18 sometimes it is the family members who do bring it
19 in.
20 I mean, it's been well documented and it's
21 not something at least in our prison that we're
22 running away from, it is a problem we have had some
23 of our inmates die of overdoses of cocaine and heroin
24 in our prisons, so it's something we've had to face.
25 Luckily, our warden is one of the few

12

2 persons who really is seriously questioning
3 segregation of inmates and in fact the director of
4 the CDC, small CDC, is questioning this because it's
5 creating more problems, really, than the CDC itself
6 can handle at this point.
7 DR. ROGERS: Just a commentary. The four
8 of you have painted just an appalling picture, man's
9 inhumanity to man in our prison system, and something
10 has gone dreadfully awry with it and we've heard that
11 loud and clear and AIDS seems almost a final straw.
12 I think you'll see that reflected in what this
13 Commission responds to.
14 DR. OSBORNE: Thank you very much for your
15 very important testimony. We appreciate you being
16 here.
17 The next panel will be Brenda Smith from
18 the National Women's Law Center and Marilyn Rivera,
19 founder of the ACE Program, which has already been
20 referred to on occasion, and we appreciate you being
21 with us.
22 If you can, as before, keep your comments
23 brief and give us a little chance to interact, we
24 really appreciate the opportunity.
25 MS. SMITH: I'd like to thank you for

2 inviting me here and I've created plenty of
3 entertainment by getting stuck in the door and what
4 I'll do is, I'll try to be very brief. You have my
5 testimony, and I think that the testimony that you
6 received thus far is really wonderful and it's really
7 done a lot in terms of my education.

8 What I'd have to say is I've come to this
9 issue fairly recently and really through the back
10 door. I am not a physician or have any experience
11 with the public health system through training. I am
12 a lawyer. Prior to being a lawyer with the Women's
13 Law Center, I was a public defender in the District
14 of Columbia, and prior to that I clerked for the
15 presiding judge of the Family Division, who's a very
16 activist judge in the District of Columbia, so I've
17 done a lot of work with children, families and with
18 women.

19 One of the reasons that I left the public
20 defender service was because I really felt that what
21 I was doing was putting my finger in the dam and not
22 really dealing with some of the larger problems that
23 brought women into the system. I felt by working
24 with the Women's Law Center I would bring a broader
25 perspective to the issues of women which I felt were

2 not being met in the criminal justice or correctional
3 setting.
4 What I have found in working with the
5 women's organization is that there are few women's
6 organizations, and I probably have to say with the
7 exception of maybe Legal Services for Prisoners With
8 Children out in California and some of the groups,
9 some of the great groups that have come up in the
10 prisons, there really are not women's groups that are
11 dealing with the issue of crime and drug dependency
12 and the toll that it takes on women and their
13 families and that's the starting point for me.
14 In trying to do some background and come
15 up with some numbers and some figures on how HIV
16 affects incarcerated women, I found that there was a
17 significant amount of difficulty, and I'm also having
18 that same difficulty with the testimony that I
19 received. What has happened is the same thing that
20 happens with women in the prison context. Because
21 their numbers are so small or viewed as so small,
22 there's very little attention paid to ferreting out
23 or parsing out information which is specific to them.
24 But there are some things that I think
25 this Commission should be aware of, and I've talked

2 about some of them in our testimony, and I think as I
3 said, that it's useful to give a brief profile of the
4 women that we're talking about.
5 Now, I have to admit that my experience
6 may be somewhat skewed because I work primarily with
7 women in the District of Columbia, and, as you know,
8 white people do not commit crimes in the District of
9 Columbia. Everybody in jail is black. We don't have
10 Latinas, very few, and so it's somewhat skewed, but I
11 do have some national information as well.
12 I think that Mark talked about up front
13 the fact that for many years there were very few
14 women in the prison and jail system, and that that
15 number has really tripled over the last decade.
16 We've gone from 13,000 women in federal and state
17 prisons in 1980 to about 41,000 now. That's about a
18 25 percent increase in figures from 1988 to 1989,
19 compared with about 13 percent increase for men. The
20 District of Columbia led the nation with an increase
21 of about 54.3 percent.
22 Now, those numbers are relatively small,
23 because we went from about 372 sentenced females to
24 about 574. And people have already talked about why
25 we're seeing that increase in the number of people

13

2 who are incarcerated.

3 The Federal Bureau of Prisons reports that

4 60 percent of the women who are in their custody are

5 serving sentences for drug offenses. In the District

6 of Columbia it's 56 percent. I just draw your

7 attention to a quote from Attorney General Dick

8 Thornburgh upon the release of some statistics on the

9 jump in the prison population. He labled the jump in

10 prison population as an indication that more

11 criminals, many in drug related offenses, are caught

12 and punished. The criminal justice system is

13 working, people who break the law pay the price.

14 I'll leave it at that.

15 Though the female prison population is

16 increasing at a much faster rate than that of the

17 male prison population, I think there are several

18 things that are different about the female prison

19 population which bear some discussion.

20 First of all, women are primarily in

21 prison for non-violent, economic kinds of offenses,

22 and even though some would disagree, I believe that

23 drug sales is a non-violent economic offense.

24 Another important difference, which I

25 think has some significant implications for

2 treatment, is that many female prisoners, I'd say
3 about 80 percent, were prisoners with children, so
4 notwithstanding what was going on out in the
5 community, they were taking care of responsibilities
6 in the community, and that continues in the prison
7 setting.
8 Even though, of course, as all prisoners
9 are concerned about their release status, about
10 parole, the primary concern that I found among many
11 of the women is what's going on with my family,
12 specifically what's going on with my children. 70
13 percent of the women in prison who have children are
14 single parents and prior to their incarceration 85
15 percent of women prisoners who had children had
16 custody of their children, compared to only 47
17 percent for men.
18 In terms of the age, these women are
19 primarily between the ages of 20 and 35 and they are
20 in their prime child bearing years. The Department
21 of Justice statistics reports that at any time about
22 eight to ten percent of the women in custody of
23 federal and state prisons are pregnant. There's
24 another number that estimates that 25 percent are
25 pregnant and post partum.

2 I won't even go into the statistics,
3 because people have talked about a lot of numbers and
4 I realize that we have some time constraints here.
5 It's included in my testimony. I'll just leave it to
6 say that many of these women are IV drug users or had
7 sexual partners who are IV drug users. Many of these
8 women have partners who have been involved in the
9 criminal justice system and who are not necessarily
10 homosexual, but have engaged in same sex
11 relationships with other men.
12 The District of Columbia blind
13 seroprevalence study, and I think there are a number
14 of reasons for that, according to them, they say that
15 it's to not have to confront all the legal issues
16 that you have to deal with for confidentiality. I
17 think if they knew how many people really were
18 infected with the AIDS virus, that they really would
19 not be able to deal with them.
20 What they have found out, though, is just
21 from their blind seroprevalence study that 14 percent
22 of male prisoners and 16 percent of women prisoners
23 tested positive for the HIV virus. Notwithstanding
24 those significant numbers, there's one health
25 educator for about 10,000 inmates and that doesn't

2 include population, it includes correctional staff.

3 Finally, what I would say is there's a

4 real need for treatment and education specifically

5 targeted to women's needs, that take into

6 consideration the reality of women's lives. Women

7 are not out there alone, they're out there with

8 families and they are supporting children and they

9 will go back to the community and they will also

10 continue to support those children. And even though

11 the numbers of women are relatively small, you also

12 have to consider that the education that women will

13 receive will also impact on those families that they

14 will educate as well as to their children, many of

15 whom are born HIV positive.

16 And with that, I'm going to leave it, and

17 then I'd like to hear from Marilyn.

18 DR. OSBORNE: Welcome, and after you have

19 had a chance to talk, we'll interact with both of

20 you.

14

21 MS. RIVERA: I just want to thank my

22 higher power at this moment for being here, and I'd

23 like to say that there are five different things that

24 I'd like to discuss with you this morning related to

25 incarcerated women who are HIV positive.

2 They are, who are the women in prison who
3 are HIV positive, why they are HIV positive, what the
4 ACE program is and how it is successfully serving
5 this population, the need for extending ACE
6 nationally and the need for increasing the number of
7 programs that service HIV positive women in
8 transition.
9 I was incarcerated for three years and
10 have another year before I complete my full sentence.
11 I rapidly graduated from having shot heroin to ending
12 up on a methadone program. I went straight to the
13 pit. I never even bothered to sniff heroin. My
14 experience as a shooter was no longer than eight
15 months. I knew I wanted to stop so I went to a
16 methadone program. I lied about how much I had been
17 using on the streets and ended up on 60 milligrams on
18 intake, which is three times greater than what I had
19 originally been taking out in the street.
20 I should have--well, this lasted another
21 eight months and I dove head into crack. Somehow I
22 discovered that crack alleviated my withdrawal
23 symptoms from methadone, and this was to become the
24 most devastating move that I had ever made in my
25 life.

2 While my habit increased and my money
3 dwindled, I committed my crime.
4 I was a drill instructor in the United
5 States Army, I served a full term and had an
6 honorable discharge. I went on to become a
7 correctional officer and decided after about a year
8 that I would accept an offer that my brother made for
9 me to join forces with him and become one of the
10 first Latino brother and sister mortuary teams out
11 here in New York City. This attempt was quite
12 successful and I served my community in this capacity
13 for about six years.
14 I ended up in a relationship with somebody
15 who was addicted to drugs and in my effort to give
16 that person a mirror image of what they gave me, I
17 began to use heroin and nodding out in front of their
18 presence. I did this because I felt I had invested
19 too much of my time, energy and emotion and finances
20 to allow heroin to separate us. I did not know what
21 I was getting into.
22 The point that I want to make to you today
23 you might have heard before, perhaps with one
24 exception. Today I come before you stronger than
25 I've ever felt before in my life. I celebrate life

2 today. I've been sober for four and a half years
3 now, and my medical status is HIV positive. I didn't
4 know that when I was in prison, but I knew that I was
5 in a high risk category.
6 I shared works, and when I was addicted to
7 crack, I exchanged sexual favors to support my habit.
8 Crack is the highest form of high that many women,
9 including myself have ever encountered. A large
10 percentage of women are going to jail for it. We all
11 know that crack is an epidemic and we know how it
12 perpetuates oppressive social and economic
13 conditions. Unfortunately, women have embraced this
14 demon crack.
15 Since 1980 to 1990, the prison population
16 has tripled. Women have turned to crack in a way
17 that they have never used any other drug before. For
18 example, women drug abusers do not have to wait for
19 their man to cop this drug, nor do they have to wait
20 for their men to shoot up, to help them shoot up,
21 like we saw back in the '60's and into the late
22 '70's. Men often shot heroin to their women, as
23 opposed to women shooting up themselves. Crack is
24 easily smokeable and it is everywhere. Not even the
25 mayor of Washington was spared from its clutches.

2 There is an incredible psychological
3 dependency to crack. As a result women, addicted to
4 crack will do just about anything to get it. This
5 explains why a large percentage also of incarcerated
6 women are HIV positive. Like myself, they, too,
7 traded sexual favors for crack, sometimes engaging in
8 unprotected sex. Some have shared needles with HIV
9 infected people without knowing it.
10 My consciousness with regards to the AIDS
11 epidemic was arisen during my incarceration. This
12 prompted the grass roots of a project designed by
13 five founding members, including myself. The AIDS
14 Counseling and Education Project is a peer based
15 project. ACE offers support services for women in
16 prison and has an educational component, certifies
17 inmates as health educators. It has a buddy system
18 for women who repeatedly go to and from the hospital
19 with pneumonia. These women were HIV positive and
20 most of the time didn't even know it.
21 ACE also has a counseling component which
22 inmates can engage in a one on one peer counseling
23 and sometimes that makes it difficult, because two
24 inmates can't be together alone at the same time
25 without being supervised. It's a privilege to

15

2 organize in prison anyway, you know, it is a
3 privilege to get together and organize this. For
4 this reason, I want to take this time to thank Elaine
5 Lord, the superintendent of Bedford Hills and the
6 AIDS Institute for our funding source, and the many
7 people who helped make ACE possible. I'm a little
8 nervous because this is like the first time I'm doing
9 it and it really makes an important part of my life.
10 ACE is an effective model that needs to be
11 considered in prisons nationally. I am appealing to
12 the state and federal government to fund more
13 programs like ACE in prisons around the country. ACE
14 is a process of empowerment. Since co-founding ACE,
15 I have dedicated my life to working towards building
16 a bridge which women can cross from prison back to
17 society.
18 As mentioned earlier, AIDS and drug abuse,
19 specifically crack abuse, go hand in hand. As a
20 result, there is a need for programs that provide
21 therapy, fostering psychological detoxification from
22 drug usage. I've been psychologically detoxing for
23 four and a half years, okay? Any form of disease
24 dealing with substance abuse is a problem that a
25 person deals with for the rest of his or her life,

2 but recognizing the problem is the first step towards
3 self help. Intensive therapy would help.
4 There is a need for programs that deal
5 with coping with life after prison. For example,
6 programs that find housing and employment for HIV
7 positive women in transition like Providence House, a
8 halfway house located in Brooklyn, New York. While I
9 was incarcerated, I was fortunate enough to have
10 surrounded myself with positive programs like ACE
11 that suited my need for growth. Other women around
12 the country need access to these similar programs.
13 When I was initially paroled, I found
14 myself out of prison with practically no support
15 mechanism. I was lucky, though, I managed to find
16 Providence House and I had the will to stick it out,
17 but there are so many other HIV positive women
18 parolees who were not as fortunate as I was and they
19 need a program to bridge their way to the point that
20 I have breached, and with that I would like to
21 conclude my testimony.
22 DR. OSBORNE: Thank you very much, we
23 appreciate the strength that it takes to testify and
24 we're really very grateful for you for doing so.
25 MS. RIVERA: Thank you.

DR. OSBORNE: Commissioners?

COMMISSIONER DALTON: It's very nice to meet you face to face. I have a question for each of you, but let me start with you.

Bedford Hills I think is a little special in the sense that they are willing to allow inmates to organize themselves and to empower themselves and they're willing to allow women back in the prison who have been through the system, and my experience is that oftentimes other prison systems, institutions aren't willing to allow that much interaction between inmates and former inmates, and I guess I was wondering what you would say to other institutions to help them see the wisdom--because that's going to be a big barrier to replicating ACE in other places.

MS. RIVERA: If you want to eliminate the increase in overpopulation in your prisons, we have to look at it on a different level, one which we probably have overseen for many years. The fact is that women have special needs, and women, treatment for women, medical and psychological are different from the needs of men, and we have to make them independent of each other, especially with women, because when categorically women go to prison, either

2 they are pregnant, they have children or they're
3 single, and one of the things that has worked for me
4 through my recovery has been therapy.
5 I was able to go back to my youth and
6 isolate these issues and identify these emotions. A
7 lot of us don't want to do that, a lot of us, that's
8 where it begins. A person has to make that
9 communication within themselves and turn that over.
10 The fact that ACE allows that, that
11 Bedford Hills allows us to go back is really
12 important, because we speak the same language as the
13 women that are going in, and we can more or less
14 empathize with the feelings that are going on there.
15 One problem, one major problem for me is,
16 though, even having been a co-founder of this
17 project, I have not been really connected with
18 exactly what's been happening with ACE. I have not
19 really been considered even after my year and a half
20 of being out here and on parole, to possibly even
21 begin to bridge this. I've taken that into my own
22 hands and I'm going to do it regardless, hoping that
23 I will be able to establish and maintain that rapport
24 with the women of the core group and Elaine Lord.
25 I've never had a problem with Miss Lord and I don't

16

2 think there will be, but I think that we need to be
3 considered as an empowermental tool.
4 Give these women the opportunity to find
5 their--to claim their voice and to find their space,
6 so that they can come out here and they don't have to
7 fall in the clutches again.
8 We forget that crack is intensely
9 psychological depending--we're not dealing with that,
10 so a woman that's been in prison will do four years
11 and won't really physically go through a lot of heavy
12 duty withdrawal, but psychologically, the first thing
13 she's waiting is to get her mega-hit once she gets
14 out here, and if she doesn't have a place, a shelter,
15 if she doesn't have a home to go to or ends up going
16 back to the home she came from which is
17 dysfunctional, she ends up going to a shelter or a
18 halfway house or she ends up lying about where she's
19 staying at just because she wants to get back out, so
20 we have to begin to design programs that meet the
21 specific needs for women that are experiencing this
22 problem, and I don't know what else to say.
23 MS. SMITH: Harlon, what I'd say is I
24 think what has to happen is it happens in increments.
25 What I've seen happen with our program is, we run a

2 similar program to ACE, but much more lawyerly, we
3 can't do the sort of things that Marilyn has been
4 able to do, and I think she's absolutely right.
5 I have absolutely no credibility to talk
6 to prisoners about drug use, about HIV infection at
7 all. I mean, I can talk to them about getting their
8 kids back, I can talk to them about strategic things
9 like that, but what we were able to do is we as a
10 group had a lot of credibility with the prison and
11 what we did, let me just say is. What we did is
12 before we even started our program, we went to the
13 prison and we talked to the women for about four
14 different times, two or three times each. We got
15 them, two or three hours each. We got them to
16 identify what their priorities were. A lot of them
17 were around domestic violence, incest, divorce,
18 custody, self-esteem issues and what we did was put
19 together a series of workshops and an educational
20 series around those things, but also the women really
21 identified AIDS as something they really wanted
22 education about and something they were not receiving
23 in the prison setting.
24 What we did then was we broke it for
25 services with another organization that trained women

2 who had been released from prison who were former
3 prisoners and who allowed those people to come back.
4 Because we were there, the prison never even thought
5 about it, they never looked at it, they never thought
6 that these were former prisoners.
7 I think that's one incremental way to do
8 it, but I also think there needs to be support with
9 current prisoners and others while they're in there
10 to build that community and I would say the approach
11 we used is one way to start and then you move people
12 along, but I think it can be done.
13 MS. RIVERA: And I think also that
14 clinical trials for women should be looked at,
15 because I mean, just because a woman's in prison, if
16 you look at where the dysfunction came from, from the
17 beginning, I mean, I wasn't born a dope fiend, okay,
18 and I didn't, I was strung out on crack, you don't
19 really understand the psychological effects of it,
20 but there is an intense, an extreme intense feeling
21 that is overwhelming, and I don't feel like there are
22 enough programs out here that are dealing with it.
23 The only type was, okay, you mandate me to
24 a treatment program, which is really great. The only
25 way that I made that work for me and not to say that

17
2 I'm here because parole mandated me, was that I had
3 to make a self conscious decision as to what I wanted
4 to do with my life and I had to feel that I was
5 worthy of something in my life, and women need to get
6 in touch with the self all over again.
7 Men and women, but specifically women,
8 because women are the primary caretakers and they're
9 the last ones that will receive treatment and one of
10 the reasons that you don't hear about women to women
11 transmission or stuff like that is because it hasn't
12 been documented. We don't have clinical trials that
13 document women's transmission. There's just not much
14 said about it, and I think that should change.
15 DR. OSBORNE: Scott?
16 COMMISSIONER S. ALLEN: I have a couple of
17 questions for Marilyn.
18 One is, what type of national network do
19 you have at this moment to get out your message? Do
20 you have any kind of structural setting to where you
21 can discuss state to state, so forth?
22 MS. RIVERA: Not at that level. They say
23 you have to crawl before you walk sometimes, right?
24 I work for the Narcotic Drug Research
25 Institute. I am an outreach supervisor at the Bronx

2 AIDS research center there. I run a support group
3 for women that we call the WOW Women, because we are
4 the Women of the World.
5 Recently, on August 1, 2 and 3 we were
6 able to communicate our information about the group
7 and personal experiences on Channel 41 with Miriam
8 Ayama, and just a few newspaper clippings and stuff
9 like that.
10 COMMISSIONER S. ALLEN: We heard testimony
11 yesterday that something like 28 percent, I think it
12 was Rikers, that 28 percent of the women felt like
13 there's nothing they could do about HIV, and that
14 seemed to be correlated with those that have been
15 sexually abused, or forced sex, and although you
16 can't make a direct correlation, but how much
17 fatalism is there within the prison setting of women
18 of saying, "I'm stuck"?
19 MS. RIVERA: When I was at Bedford from
20 1986 to 1989, and before the ACE project took off, I
21 saw approximately 20 women die from some symptom of
22 the HIV virus, because of not enough medical
23 information or up to date medical facilities--the
24 facility wasn't equipped to handle the amount of
25 women that were HIV positive or coming in, or the

2 fact that you have women in there that had already
3 been HIV positive and that were using drugs and were
4 infecting one another from using syringes.
5 COMMISSIONER S. ALLEN: One more question.
6 Do you have any contact with women's shelters in the
7 city? I know your program is specifically for those
8 what are HIV positive, but those in higher risk
9 behavior and those that have been abused, do you have
10 some type of interaction?
11 MS. RIVERA: There's one particular
12 shelter in the Bronx called Willow Shelter that we
13 deal, we give them a lot of support and education.
14 There are just not enough beds, there are just not
15 enough services. Women that come out of prison that
16 end up in shelters, okay, don't have money, you have
17 to start from the very beginning, because you've lost
18 a lot of your identification, you have to go get your
19 Social Security card, your birth certificate, and
20 then you have to have a resume to get a decent job,
21 and it's the whole recidivism thing, it's the whole
22 revolving door thing.
23 They're not prepared with life skills, and
24 what I'd like to offer in the future, because I've
25 been flirting with the design of a program I call

2 "Complete," basically because I've made a complete
3 circle in my life and it's a community organization
4 motivating people long enough to educate. I feel if
5 I could capture your attention and yourself long
6 enough to provide you and raise your consciousness
7 and begin to empower you through the arts, through
8 theater, through writing, through poetry, through
9 music, through education, through intention therapy,
10 through support and counseling services, then you
11 become a woman that will deal with the issues, and
12 that will enable you to think about where you are
13 today and what you have to offer society now.
14 That's a question I ask myself. It's not
15 what they can do for me, it's where do I fit and what
16 can I offer society at this point, what is
17 meaningful.
18 COMMISSIONER S. ALLEN: Thank you.
19 DR. OSBORNE: Thank you very much.
20 MS. RIVERA: Thank you very much.
21 DR. OSBORNE: Now the Commissioners will
22 take an abbreviated lunch break and we'll try and get
23 back closer to schedule by starting up again at 1:30,
24 if we can.
25 (Whereupon, at 12:45 p.m., a

luncheon recess was taken.)

AFTERNOON SESSION

(1:40 p.m.)

18

DR. OSBORNE: Let me ask the Commissioners who are here to please be seated so we can get started. We're running later and later and we have airplanes and things to think about and I don't want to cut our important witnesses short.

This afternoon, we'll start with Judy Greenspan, who is the AIDS information coordinator at the National Prison Project of the ACLU Foundation, who will total about fifteen minutes to get a chance to hear from her and also to ask questions.

MS. GREENSPAN: First of all, I just want to say, it's definitely an honor to be here and I appreciate this opportunity and also all of the prisoners who responded to my plea for testimony and information are also honored to be here. And in fact, I really regard my testimony as really a summary of complaints, injustices, faced by thousands of HIV infected prisoners in jails and prisons around the country, and if this could be the beginning of a development of a rational, sane, medically enlightened response to HIV infection in prisons, then we'll have accomplished quite a task.

2 AIDS and HIV in prisons has meant three
3 things for prisoners: Lack of adequate medical care,
4 frustrated attempts at AIDS education and plenty of
5 discrimination.
6 For two years, I have been innundated with
7 hundreds of letters from prisoners around the country
8 complaining of some of the worst abuse and I think
9 we've heard a lot of it today, so I'm not going to
10 give you a list, but I will say that all of them have
11 said to me in their letters and also a number of
12 phone calls, because we are one of the few agencies
13 that receive and accept collect calls from prisoners,
14 that they very eloquently can tell their own story,
15 and I would hope that the Commission would look into
16 some of the direct testimony.
17 Having AIDS or HIV is bad enough, but you
18 combine that with being in prison, and you have a
19 very serious and deadly combination. Prison and jail
20 administrators are now only beginning to take small
21 steps to deal with this epidemic, and I believe and
22 the prisoners are appealing to you to play a critical
23 role, that the National Commission must play that
24 role recommending a sane and national policy for the
25 management of this disease in jails and prisons.

2 President Reagan, as you may remember, had
3 a response to AIDS in prison, and that was to set up
4 mandatory testing or to urge mandatory testing, and
5 we've seen after three years that it really has not
6 led to better policies. It's led to segregation,
7 it's led to a highly stigmatized and discriminated
8 against population.

9 Reading the letters has only convinced me
10 more that there's a very serious situation developing
11 in prison. Catherine Hanssens has talked to you
12 about Gregory Smith, who is the prisoner in New
13 Jersey who was recently convicted of attempted
14 murder, sentenced to 25 years in jail, a death
15 sentence, for allegedly biting a guard. But these
16 cases, it's not just Gregg Smith, it's many
17 prisoners, there have been over a dozen cases in the
18 past year of prisoners who have been charged with
19 attempted murder, attempted capital murder, assault
20 with a deadly and dangerous weapon for allegedly
21 biting a guard, and I will emphasize with you and I
22 think we have the example of Rikers Island to prove
23 it, that oftentimes in prison a prisoner is assaulted
24 and beaten by a corrections guard for whatever
25 reason, and that prisoner is charged with assault to

2 cover up this crime, and I think that's what's going
3 to surface with the Rikers Island fiasco, that these
4 prisoners were brutalized by these guards, but
5 combine that with HIV positivity, and it doesn't
6 become a disciplinary infraction for that prisoner,
7 it becomes an attempted murder charge, it becomes
8 perhaps a death sentence and the prisoner is
9 discriminated against.
10 Education is a real problem in prisons.
11 It's not being done. I don't really care what the
12 results of the NIJ study on AIDS in prison is. My
13 word from the prisoners, and I believe them, that at
14 the very most, prisoners are still seeing that old
15 film, "AIDS: A Bad Way to Die," which sends
16 absolutely the wrong message to them.
17 They're receiving one or two pamphlets,
18 maybe they're receiving the Surgeon General's report,
19 none of which deals directly with them and it
20 certainly doesn't deal directly with the fact that
21 many prisoners unfortunately operate at a very low
22 reading level or are illiterate, so there's really
23 not an educational message.
24 So what the prisoners have done, they've
25 been themselves involved in peer education and

2 counseling efforts like Marilyn Rivera testified to
3 about Bedford Hills. Only for the men in New York
4 State particularly, organizing and setting up peer
5 education counseling efforts has met with--their
6 effort has been severely obstructed by the New York
7 State Department of Corrections, and I have two
8 examples that I want to bring to your attention.
9 One is the case of David Gilbert, who is a
10 prisoner in New York State, who has been moved since
11 I've known him, over the past two years he's been
12 moved four times, and he is one of the original
13 organizers of the AIDS education effort at Auburn and
14 since that time he's visited four other institutions,
15 just having been moved about three weeks ago.
16 Cruz Salgado, and some of his testimony
17 and letters are in your packet which I hope you can
18 get, because I know some of them were given out, Cruz
19 Delgado was recently moved from Greenhaven to Attica,
20 and fortunately I will say that these prisoner
21 educators and organizers wherever they go are
22 organizing AIDS education programs, but it's not
23 being met with a very enthusiastic response by the
24 Department of Corrections.
25 There are serious problems with medical

2 care, and some of the letters I've included with my
3 testimony address that. The prisoners complain of
4 everything from insensitive physicians' assistants to
5 the fact that they can't get their medicine, to the
6 fact that there's no confidentiality. Oftentimes,
7 prisoner's medical records are discussed when there's
8 a big crowd around.
9 Many medical care providers in prison
10 still are afraid of AIDS and HIV and won't touch, you
11 talk about hands on care, won't go near the prisoner,
12 won't touch the prisoner, won't talk to the prisoner,
13 except in the presence of a corrections guard, and of
14 course that means that there's really no
15 confidentiality.
16 I'm sorry that Dr. Moritsugu had to leave,
17 because I wanted to bring to his attention some of
18 the problems of HIV positive prisoners and prisoners
19 with AIDS in the federal system, but I will say that
20 it is an extreme problem, that of discrimination
21 against people for release into the community, into
22 halfway houses, parole discrimination based on the
23 fact that the federal government still insists on
24 testing people on exit, and also that it is an
25 extremely horrendous problem, the problem of

2 prisoners dying with AIDS, particularly in the U.S.
3 Medical Center at Springfield, and I would really
4 urge you to not only read the articles, but if
5 there's any way you could visit the Springfield
6 Medical Center, any way you could take testimony from
7 HIV positive prisoners and those with AIDS at
8 Springfield and learn about the lack of quality of
9 care they're receiving. There's no reason for
10 prisoners to die in jail. They should be released.
11 Anyway, I'll leave you with that, and just
12 say that I think that there are a lot of very good
13 people who are locked up in prison who are really
14 beginning to make a dent, who are doing their own
15 AIDS education efforts. I think they need our
16 support and together we can begin to tackle fear of
17 AIDS, which I think is just as dangerous as AIDS
18 itself.
19 DR. OSBORNE: Thank you very much and
20 thank you for your important work. It will be a
21 privilege to get a chance to participate in some of
22 the correspondence.
23 Questions?
24 COMMISSIONER DALTON: You mentioned Cruz
25 Salgado, said he was transferred from Greenhaven to

2 Attica. Was he the ones involved with Hispanics
3 United for Progress?
4 MS. GREENSPAN: He's one of the founders.
5 COMMISSIONER DALTON: That was an
6 extraordinary group of inmates able to bridge not
7 only a gap between infected and non-infected, but
8 between black and non-black inmates. Did his
9 transfer have something to do with his involvement in
10 HUP?
11 MS. GREENSPAN: We believe that. There's
12 no way to know, they always say it's for security
13 reasons and they won't talk about it. They have the
14 right to transfer anyone they want anywhere they want
15 and they have all the institutions to do that, and
16 most of them are in these remote areas in New York
17 State. Prisoners are transferred without any notice
18 and without notification and without any due process
19 hearings.
20 We believe it's because he was very
21 outspoken and very visible within the system, and
22 Greenhaven to this day are hostile to the effort, et
23 cetera, to organize Hispanics United for Progress.
24 COMMISSIONER DALTON: It's ironic, because
25 it seems to me that organization has done more for

2 maintaining peace inside that facility by sort of
3 breaking down barriers and giving inmates a sense of
4 their own self worth and some control over their own
5 lives, and so it certainly is backwards, it seems to
6 me, even in terms of control of an institution.
7 MS. GREENSPAN: Right. And he along with
8 David Gilbert were very active in organizing a
9 program at Attica, which unfortunately because there
10 was a reaction to some brutality on the part of
11 guards, there was sort of an institution wide
12 demonstration, now they're sort of back to square one
13 and in the meantime they went and transferred David
14 Gilbert out, so now Cruz is on his own at Attica, but
15 organizing.
16 DR. OSBORNE: I have a question that's
17 been growing over the last day and more, but
18 especially in the testimony that we've heard, and
19 that is, do you have any sense of the--I get a sense
20 that there's a discontinuity between the Department
21 of Corrections or its equivalent and then the medical
22 personnel to the extent that they are represented
23 within the Department of Corrections, that there may
24 be complete ignoring of medically appropriate advice.
25 On the other hand, sometimes I get a sense

2 that the medical advice may not have been as astute
3 and sensitive as we would want.
4 Do you have any way of helping me with
5 that? To what extent are we dealing with the
6 discontinuity between two systems that don't talk
7 well to each other, health care within corrections as
8 opposed to corrections personnel themselves and to
9 what extent is there sort of a partnership in things
10 not working as well as they might.
11 For instance, HIV education is a very
12 obvious place to ask the question, because it doesn't
13 take the resources that might necessarily be there to
14 fulfill other medical qualifications.
15 MS. GREENSPAN: See, it's a very complex
16 question, because different states do different
17 things with medical care. Some of them contract out.
18 Now, within that contract some of them say, okay,
19 you're going to provide the education, meaning the
20 medical care providers, and in some of them they say
21 no, you're not going to do it, we're going to do it.
22 What I found is that the medical services
23 department tends to be, they don't set the policy,
24 they carry out the policy, but that the
25 administrators are a lot easier to talk to and deal

2 with than the Department of Corrections, which takes
3 sort of a very penological, more corrections type of
4 approach.
5 What I have found, though, however, in
6 terms of successful education programs is that they
7 are really only successful when the system goes
8 outside itself, when it goes out into the community
9 to AIDS service organizations, even to the Department
10 of Public Health, and brings them in. When it's the
11 medical care providers, they're too wrapped up in
12 what their financial situation is.
13 I've heard too many times prisoners
14 writing and saying the doctor informed them they
15 can't get AZT because it costs too much money and at
16 this point what I'm alarmed about is the fact that
17 most prison systems have not taken to heart the new
18 FDA guidelines on AZT. They are not administering
19 AZT for asymptomatic HIV positive. Some systems are,
20 I know New York State is, New Jersey is supposedly is
21 and now what Catherine Hanssens says, it's still not
22 accessable in the state of New Jersey, so there's a
23 real problem with that, they're always worrying about
24 their pocketbook.
25 And then, most unfortunately, the

2 Department of Corrections is too much worried about
3 management and security to really deal effectively
4 with, and besides the fact that prisoners do not
5 listen to whatever anybody within the Department of
6 Corrections does or says, so that I think the most
7 effective education is the peer education effort,
8 with the assistance of the outside AIDS service
9 organizations.

10 DR. OSBORNE: Thank you, that's very
11 helpful. Diane?

12 COMMISSIONER AHRENS: I don't know if this
13 is so much a question as a comment, but as I've
14 listened, particularly in terms of state systems, and
15 I think that's really what we're talking about by and
16 large today, with one federal exception, is that
17 there doesn't seem to be good communication, any kind
18 of substantive linkage between State Department of
19 Corrections and State Departments of Health, because
20 we've heard in some states where the Departments of
21 Health that we've heard about in prior hearings, and
22 in those same states the Department of Corrections
23 seemed to be going in opposite directions with
24 respect to this issue, and I guess one of the things,
25 and you may wish to comment upon this, but one of the

2 things I think this Commission needs to address or
3 call attention to, is that desperate need for these
4 two separate departments within each state to talk to
5 each other at the very highest level.

1

6 DR. OSBORNE: That's what my question was
7 getting at, but I was also trying to get at whether
8 if they tried to talk to each other, would it work,
9 how different are the cultures, and your answer
10 suggests that they may be a little too different, and
11 you may need a third party communicator or something.
12 Charlie?

13 DR. KONISBERG: I'll share a kind of a
14 personal experience during our last legislative
15 session in Kansas that suggests that the cultures are
16 a bit different.

17 The Department of Corrections, together
18 with others involved in law enforcement banded
19 together to create a proposed bill to go through the
20 legislature which would have provided notification of
21 fire and police and other first responders, which,
22 while it may have some public health and medical
23 merit, the way it was written was not only medically
24 irrational, but had all sorts of confidentiality and
25 other problems you can well imagine.

2 When we sat down to talk with those
3 people, hard now how to describe the difference in
4 culture. I don't think I want to use the word in
5 this setting that I used in private, but suffice it
6 to say that they weren't tracking with medical and
7 public health folks and had deliberately avoided
8 getting input not only with us, but from their newly
9 hired part-time medical director at the State level,
10 who coincidental and perhaps unknown to them, was
11 probably one of the few physicians in Kansas really
12 interested in AIDS issues. They particularly
13 excluded him, but the AIDS issue was put under the
14 guise of well, let's talk about mononucleosis, which
15 is where it got really irrational; hepatitis, which
16 they ignored before.
17 The point is there truly is a cultural gap
18 that's extremely wide and I'm not about to know how
19 to bridge that, except that what I heard in the last
20 two days suggests to me that at least as a state
21 health official I have to go back and try a lot
22 harder.
23 MS. GREENSPAN: I really think the key is,
24 and I think the states have been left to sort of do
25 whatever they want, because of a real lack of a

2 federal policy, and I think that the main thrust of
3 the federal policy has to be education, and it has to
4 be that this is--and it has to be talked about as a
5 very important weapon to fight AIDS.
6 I think education and early treatment and
7 voluntary testing, those three things are what is
8 lacking in most prisons. They still, most prisons
9 and jails still want to lean back on that mandatory
10 testing, and once they've identified the population,
11 then who cares about education? They don't
12 understand. You know, universal precaution for them
13 means you wear gloves when you're around somebody HIV
14 positive.
15 In the state of Alabama they only have
16 gloves in the HIV units. The only place where they
17 used universal precautions and Alabama is an extreme
18 case, but it's that type of thinking. And there is a
19 gap, yes, between the medical and between the
20 correctional, but most unfortunately, what I found is
21 that all too often the medical will defer. They will
22 not take a strong stand and that's why you really
23 need an outside force and I don't know if it's just
24 the Department of Health or if it's involving some of
25 these AIDS advocacy groups that have grown up and

2 that are private organizations, but there has to be
3 some people coming in from outside with a rational
4 policy.
5 DR. KONISBERG: You have to be, what I
6 guess I learned about this also, you have to be
7 vigilant or these things will slip through. In our
8 case we found the State Medical Society to be an
9 outside force that didn't have to worry about any
10 political problems, but they had gagged their own
11 medical director, there was no question he was
12 deliberately left out of it, but we would have
13 appreciated more guidance I think, June, from the
14 federal sources, because I felt almost defenseless
15 and nearly panicked in trying to quickly come up with
16 some guidance and we couldn't find it any place, we
17 had to really work on it from scratch.
18 DR. OSBORNE: Jim Allen.
19 COMMISSIONER J. ALLEN: Are you aware of
20 any state in which the medical care or the medical
21 program for the state correctional facility comes
22 under the aegis of the Department of Health rather
23 than the Department of Corrections, or whatever the
24 analogous organizations are?
25 MS. GREENSPAN: I'm not aware of any state

2 where that's the case. There might be, but I don't
3 know.
4 COMMISSIONER J. ALLEN: There are states
5 we've heard from today, as well as in the federal
6 system, although there are public health officers
7 assigned to the Department of Justice, it all comes
8 under the corrections side, and I think what Dr.
9 Konigsberg was just alluding to, saying we need to go
10 back and have the state health departments try a
11 little harder, seems to me we've got 50 state health
12 departments as well as those of the trust territories
13 that we need to begin working with, because I don't
14 see any possibility of the medical side being under
15 the direction of the correctional side having the
16 resources and the individual or the independent
17 flexibility to put into place the kind of leadership
18 and the kind of programs that are really needed.
19 So somehow we've got to find a way of
20 really empowering the state health departments to
21 become involved in this and get the state
22 legislatures to give them the authority to allow them
23 to do something in this arena.
24 MS. GREENSPAN: Just one other thing,
25 there's just something to consider in dealing with

2

2 AIDS and HIV with prisoners. I think it's generally
3 understood in the outside world that people survive
4 longer when they can actively participate in their
5 care and their treatment, and this is what is being
6 denied prisoners. It's certainly being denied with
7 all diseases, but with HIV disease, which is as we
8 know, believed to be fatal in most cases, it
9 certainly would be fiscally rewarding to the
10 institution to have these prisoners live longer, I
11 would think, although they don't act that way, but if
12 the prisoners, if there was a way that the prisoners
13 could be involved in their care and treatment and
14 their education, and I think that at least from the
15 letters I've received, I've been literally blown away
16 by their interest and their eloquence and their
17 knowledge of HIV disease.
18 I think that they need to be able to play
19 that role, and that would really help their situation
20 and it would perhaps even begin to turn around some
21 of the miseducation and misinformation on the part of
22 the corrections staff.
23 DR. OSBORNE: Thank you very much. This
24 is very helpful testimony.
25 I will now ask the next panel to join us

2 at the table, if you would.

3 Bob Levine from Yale; Victoria Sharp from

4 St. Clare's; Ann Graham, FDA, and Billy Jones from

5 Macro Systems, and if I could suggest that you

6 testify seriatum and then once we've had a chance to

7 hear from each of you, that will give us a chance to

8 interact with the whole group.

9 As I commented in the morning and some of

10 you heard me, the Commission likes best to have a

11 chance to read your testimony in detail and will if

12 we have it written, but if you could sort of

13 summarize that and make other points that you would

14 like, but then leave as much time as possible for an

15 opportunity to interact, that's our preferred mode.

16 Welcome.

17 DR. LEVINE: Thank you. Thank very much.

18 I'm Robert Levine. I hope that you have my written

19 testimony. I plan to have my--what I say now is

20 going to be quite brief. I want to address the

21 concerns that prisoners have little or no access to

22 randomized clinical trials, and also little or no

23 access to investigational new drugs through such

24 mechanisms as treatment IMD, parallel track and

25 expanded access.

2 The problem is not one of federal
3 regulation. As you know, the Food and Drug
4 Administration has no relevant regulations, and I'll
5 explain why not soon. The regulations of the
6 Department of Health and human services permit, and
7 now I'll quote, "...research on practices, both
8 innovative and accepted, which have the intent and
9 reasonable probability of improving the health or
10 well-being of the subject." Further, they explicitly
11 approve assignment of prisoners to control groups
12 which may not benefit individual subjects.
13 If all one did was to read the federal
14 regulations, one would almost certainly conclude that
15 there's no problem at all. But there is a problem.
16 The problem has much more to do with the regulations
17 as regards Phase 1 drug trials. The HHS regulations
18 and the now inoperative FDA regulations make it so
19 burdensome on the investigators and also on the
20 sponsors to do Phase 1 drug trials, that those
21 interested in working with the development of new
22 drugs have simply abandoned the prison system.
23 I'm not here to advocate doing Phase 1
24 drug trials on prisoners, but it's because of that
25 that the people from the pharmaceutical industry and

2 others who have an interest in working with
3 investigational drugs have just left the system. And
4 they've left nobody behind who has the motivation to
5 deal with investigational new drugs and all of the
6 red tape involved in getting these things, filling
7 out the forms and making them available to sick
8 people.
9 Why do the regulations discourage Phase 1
10 drug trials? Well, that's what my written testimony
11 is all about. My written testimony has mostly to do
12 with a historical development of attitudes towards
13 research involving prisoners, beginning in ancient
14 Persia and ending in Bethesda, Maryland in 1976. I'm
15 not going to--well, you must know I don't have the
16 time to involve you in that now, but I think it's an
17 interesting history and it's relatively brief, given
18 the time span.
19 Briefly, here are the highlights of this
20 history: When the National Commission met to write
21 recommendations for regulations for research
22 involving human subjects, and more specifically for
23 research involving prisoners, they had no intent to
24 preclude randomized clinical trials, no intent to
25 preclude making investigational new drugs available

2 to prisoners. In fact, if you read the commentary
3 under their various recommendations, they expressed
4 great concern that some of their recommendations
5 might in fact make it difficult for these prisoners
6 to get access to these drugs which the Commission
7 viewed as having therapeutic benefit, even fifteen
8 years ago.

9 The atmosphere in which they were working,
10 though, was an almost homogenius anti-prisoner
11 research sentiment around the world. This developed
12 in the aftermath of the Nuremberg trials of the Nazi
13 war criminals. After all, what they were all about
14 is research involving prisoners. In addition, in the
15 United States, there was a rising wave of popular
16 opinion opposed to research involving prisoners.
17 This was fanned by such things as Jessica Mitford's
18 book, "Kind and Usual Punishment."

19 Shortly before the Commission was
20 convened, there was the Kaimowitz case in Michigan,
21 having to do with corrective or therapeutic
22 psychosurgery on a prisoner, amygdalectomy, which was
23 designed to cure compulsive aggression. This
24 attracted a lot of attention in the newspapers, and
25 finally while the Commission was deliberating its

report on research involving prisoners, the store broke about the Atomic Energy Commission testing the effects of radiation on prisoners' testicles without their awareness, in the prison system.

All of these things taken together created a powerful negative attitude toward research involving prisoners.

I also believe that the Commission had an implicit agenda which was not published with their reports. I think that they thought that they could bring about prison reform by setting up a number of conditions that had to be met in order to get authorization to proceed with Phase 1 drug testing. It had to do with single bed cells, access to various health facilities and so on.

I think the Commission overestimated the investment of the drug industry in prison research. They thought if they set up these conditions then the drug industry would take the lead in reforming the prisons so that they could continue to do their research. They were wrong, they certainly did not anticipate what actually happened, and that is a massive exodus from the prison system of people from the pharmaceutical industry. As one prisoner put it

2 so well, all they succeeded in doing was getting the
3 only people out of the prison system that gave a damn
4 about the health and well-being of the prisoners.
5 I suggest to you that no matter what
6 policy change you come up with now, the fact is that
7 most prisons don't have doctors in the prisons that
8 have a vested interest in drug development. They
9 don't have people in the prisons who are interested
10 in doing randomized clinical trials.
11 Parenthetically, I should say that there never were
12 randomized clinical trials in prisons. That's not
13 the sort of research that was done there, but at
14 least while there were the drug industry doctors in
15 the prisons doing Phase 1 trials, there were people
16 there who could also tend to the health needs of the
17 prisoners.
18 I've already mentioned that there are no
19 more doctors in the prison who had the motivation to
20 deal with the bureaucracy and red tape involved in
21 making investigational drugs available to prisoners.
22 If I may, I want to close with a couple of
23 historical footnotes. I went with the Commission on
24 its site visit to the Jackson State Prison in
25 Michigan. There we were greeted by a group of

2 mandatory lifers, who agreed to talk with us. The
3 leader of the group, the spokesman for the group,
4 began by saying, "Ladies and gentlemen, I hear you're
5 from the National Commission for the Protection of
6 Human Subjects of Biomedical and Behavioral Research.
7 I want you to know that you're in a place where death
8 at random is a way of life. We've noticed that the
9 only place that people don't die here is in the
4
10 research unit. Just what is it you think you're here
11 to protect us from?"
12 Subsequently, after the FDA published its
13 highly restrictive proposed regulations, it was the
14 prisoners in this very same prison, the Jackson State
15 Prison, that initiated the lawsuit, Fante and the
16 Upjohn Company, versus the prison system. FDA,
17 rather than arguing the case, withdrew, or in their
18 language, stayed indefinitely the effective date of
19 the regulations.
20 What the prisoners were complaining about,
21 the central core of their argument, was that
22 restrictive regulations on research involving
23 prisoners was an unconstitutional deprivation of
24 their liberties, that without due process, they were
25 deprived of their right to be research subjects. The

2 FDA then reproposed regulations removing most of the
3 objections or the passages from the earlier regs that
4 the prisoners found objectionable, but what they did
5 instead is inserted a compelling reason standard,
6 while in the preamble to their first proposed
7 regulations, they said they had not put in a
8 compelling reason standard because it was too strong
9 a standard, that they thought nobody would ever be
10 able to meet it.
11 This is what signals to the pharmaceutical
12 and drug development community the intention of the
13 FDA never to permit drug research in prisons. It's
14 the installation of this word, this standard, that
15 earlier they had said was such a high standard that
16 nobody would ever be able to meet it.
17 That was back in 1981. There still are no
18 regulations.
19 Thank you very much.
20 DR. OSBORNE: Thank you very much, Bob.
21 It's a fascinating start to this discussion and a lot
22 of information of which I wasn't terribly familiar
23 with.
24 DR. SHARP: Good afternoon, my name is
25 Victoria Sharp. I would like to begin today by

2 thanking the Commission for inviting me here. The
3 need to review the treatment of prisoners suffering
4 from AIDS is great and I sincerely hope the
5 Commission will be able to assist those of us
6 involved in direct care of inmates in improving the
7 quality of medical treatment currently available to
8 prisoners with AIDS.
9 Throughout your travels around this
10 country, you have seen some of the devastation this
11 horrible epidemic has caused in our communities. You
12 have heard the despair all too frequently present in
13 the voices of those suffering from AIDS, and the
14 frustration of so many health care providers who are
15 attempting to fight this disease. I can only add my
16 voice to theirs and tell you that I have known no
17 greater challenge of the physician than that created
18 by this epidemic.
19 I have rarely seen such suffering nor felt
20 so keenly the limits of medical science and of my own
21 skills to stem this destruction of lives to soothe
22 the pain and to cure the sickness of my patients. We
23 have known this disease for ten years and we are
24 still all too often reduced to guesswork in treating
25 many of its effects.

2 In 1990, the fact remains that we have no
3 tried and true treatment for a disease which the
4 World Health Organization tells us has taken 800,000
5 lives and which will take too many more. In the
6 absence of widely accepted and proven methods of
7 treatment, the medical community has been forced to
8 rely on a collection of drugs which are often still
9 in the stage of experimentation and trial. While
10 this is certainly an uncomfortable and frustrating
11 position for the physician treating these infections,
12 our discomfort cannot compare with the frustration,
13 anxiety and very real pain of our patients. In this
14 epidemic, as in no other, have we, the medical
15 community, been forced to recognize that alleviation
16 of suffering is our paramount objective, and that our
17 patient is our partner in trying to achieve this
18 goal.
19 The situation as I have stated it thus far
20 is true for all the patients I and my fellow
21 physicians have treated. There is a population
22 although suffering from this disease, however, who
23 face an even greater battle to access what few drugs
24 are available for the treatment of their illness. I
25 use the term "available" improperly, I fear, for with

2 prisoners with AIDS these drugs are more often than
3 not unavailable.
4 As medical director of the designated AIDS
5 center at Albany and in my current position as
6 medical director of the Spellman Center for HIV
7 related disease here in New York, a large group of my
8 patients are prisoners with AIDS from the New York
9 State correctional system. As people suffering from
10 this dread disease, they have few options for
11 treatment. As prisoners, they have even fewer.
12 I offer a few examples. Mr. F, a patient,
13 a 30 year old black male who we saw early in 1987 at
14 Albany Medical Center, was diagnosed with cryptoccal
15 meningitis. He developed a severe toxicity to
16 Amphotericin B, an antifungal treatment used to treat
17 cryptoccal meningitis. The only acceptable
18 alternative, a drug called Fluconazole, was available
19 at that time only through a clinical trial. Without
20 treatment, cryptoccal meningitis is uniformly fatal.
21 Another individual, Mr. R, a 25 year old
22 Hispanic male we had followed at St. Clare's New
23 York, had CNV ritinitis, unresponsive to Ganciclovir.
24 The only other therapy, Foscarnet, was available only
25 through a clinical trial. Without treatment, CNV

2 retinitis will progress and cause blindness.

3 The exclusion of prisoners from clinical
4 trials is to some extent quite understandable when
5 recalling the past history of clinical research in
6 incarcerated populations. Such research was too
7 often characterized by a callous disregard for the
8 rights of prisoners to informed consent and freedom
9 from coersion.

10 We owe it to our patients not to forget
11 the abuses of the past but in recalling them, strive
12 to guarantee their rights, while facilitating their
13 access to needed treatment, even if the treatment is
14 in some form still experimental. The task of
15 balancing the rights of a prisoner, our duty to
16 protect them from discrimination and abuse and our
17 desire to facilitate access equal to that of the non-
18 incarcerated patient to medicine still on trial is an
19 extremely difficult one, but we cannot allow the
20 complexity of our task to overwhelm us and thereby
21 allow the current conditions to exist.

22 I would therefore like to offer the
23 following suggestions:

24 Prisoners as a population should not be
25 the subjects of any particular trials solely on the

2 basis of their status as incarcerated persons. The
3 fact that they are incarcerated, however, should not
4 exclude them from trials which are being offered to
5 the general population.

6 Accessibility to drugs on clinical trials
7 is limited, regardless of whether or not a person is
8 incarcerated. The extraordinary requirements of
9 administering these protocols create these limits and
10 many institutions who are committed to treating the
11 poor and underserved communities do not have the
12 resources to meet these requirements.

13 If the Commission makes any
14 recommendations regarding the allotment of public
15 funds, I strongly urge them to suggest that monies be
16 used to assist institutions who are providing
17 services to underserved populations, such as
18 prisoners, to meet the criteria to conduct clinical
19 trials.

20 The extraordinary requirements of which I
21 speak by their nature guarantee a higher quality of
22 medical care, whether the participants are
23 incarcerated or not. In this respect, there will
24 always be issues of coersion, however subtle. I
25 recommend that the Commission urge institutions who

2 plan to offer clinical trials to prisoners to
3 consider the issues raised by the Prisoners Rights
4 League; living conditions, amenities, absence from
5 the correctional facility, use of placebos,
6 consequences for parole status and possible
7 discrimination against certain segments of the inmate
8 population.
9 Clinical trials involving the
10 participation of inmates should be administered by
11 major medical providers, preferably those who have a
12 strong academic component which can assist in
13 conducting quality monitoring and review activities.
14 Clinical trials should not be administered by the
15 health services department of Correctional
16 facilities, unless under the auspices and direct
17 supervision of a larger medical institution separate
18 from the Department of Corrections.
19 I would like to conclude by suggesting
20 that our greatest responsibility is to create a
21 system which delivers basic quality care to everyone,
22 rich and poor, incarcerated or not.
23 Regrettably, with a disease such as AIDS
24 for which so few treatment options exist,
25 experimental drugs are too often the basic, at times

2 the only treatment option we can offer. The
3 obligation which I believe the state has to guarantee
4 quality medical care to all is even greater when
5 applied to those we imprison. They are our wards.
6 In removing them from society for our protection, we
7 assign ourselves as their protectors. In our
8 performance of that duty, as in the care of those
9 suffering from a horrible disease, will we be judged
10 as a society.
11 Thank you.
12 DR. OSBORNE: Thank you very much.
13 MS. GRAHAM: Good afternoon, I'm Ann
14 Graham from the Food and Drug Administration. I'd
15 like to thank you for your invitation to appear
16 before the Commission today. My remarks are
17 specifically addressed to FDA regulations governing
18 clinical research involving prisoners and I'd like to
19 state up front that FDA has currently no prohibitions
20 against prisoners being enrolled in either
21 therapeutic or non-therapeutic research protocols.
22 I'd like to briefly pass over the
23 regulatory history that Dr. Levine has quickly
24 mentioned, it's in my written testimony, and I
25 believe you have a copy of it.

6

2 There are, however, several other
3 treatment options available to prisoners and other
4 subjects of clinical trials.
5 The investigational new drug regulations
6 were finalized in 1987. These regulations include
7 new provisions establishing the treatment IND. Under
8 the treatment IND mechanism, certain investigational
9 drugs for which there is promising evidence of
10 effectiveness are made available for use in the
11 treatment of patients who are suffering from
12 life-threatening or serious diseases for which there
13 is no known alternative effective treatment and that
14 certainly includes AIDS, and is specifically
15 mentioned in the treatment IND regulations.
16 Six AIDS-related therapies, some of which
17 have been approved and we have discussed earlier,
18 have been granted treatment IND status to date. They
19 are Trimetrexate, Gancyclovir, aerosolized
20 Pentamidine, Erythropoietin, dideoxyinonsine (ddI)
21 and pediatric AZT.
22 A second new development is the parallel
23 track or expanded access proposal that was recently
24 published in the Federal Register of May 21 of this
25 year for comment. This proposed policy statement

2 developed by the Public Health Service with
3 significant input from community advocates, industry
4 reps, the research community and others, proposes a
5 means to provide for wider, earlier distribution of
6 potentially life saving investigational therapies to
7 patients who have AIDS. It is proposed that these
8 drugs will be offered under certain conditions to
9 AIDS patients earlier in the drug development process
10 to make them more widely available to people with
11 AIDS and HIV related diseases, who have no
12 alternatives and who cannot participate in controlled
13 clinical trials.
14 There are eight stipulated criteria for a
15 drug to qualify for expanded access and they include,
16 but are not limited to the sponsor's willingness to
17 make the drug available and to demonstrate the drug
18 availability for both the expanded access and the
19 ongoing clinical trials will not be jeopardized.
20 A third development is the federal model
21 policy for the protection of human subjects of
22 research. This is in its final stages of getting
23 cleared through seventeen federal agencies, after
24 many years of protracted delays, and we are
25 optimistic as I speak today that we will get this

2 finalized by the end of this fiscal year.
3 We are aware, anecdotally, of several
4 community based research programs that have tried to
5 involve prisoners in treatment protocols using
6 investigational drugs; California, I believe Rhode
7 Island, and Louisiana. They have encountered
8 logistic problems at the local level and at the state
9 level, and we have given guidance to those groups, we
10 have participated in community based research
11 workshops. Those efforts are not going well, and are
12 essentially defunct as we speak now.
13 FDA does have some educational programs,
14 and I'd like to explain that when we have
15 investigational new drug applications at FDA, we are
16 not allowed to disclose those. It's proprietary
17 information unless the sponsor discloses that
18 information. The FDA, along with the National
19 Institutes of Allergy and Infectious Diseases, CDC
20 and the drug sponsors have coordinated their efforts
21 in establishing an AIDS clinical trial information
22 service, ACTIS. By calling 1-800-TRIALS-A, current
23 information concerning clinical trials of commercial
24 and federally sponsored research is available.
25 Information of the location of the trial,

2 the responsible clinical investigator, protocol
3 rationale, methodology and duration of the study are
4 all available through ACTIS. We also publish the
5 availability of treatment IND's in the Journal of the
6 American Medical Association, and I don't know how
7 widely that's read by others outside the medical
8 profession, but we do provide press releases and talk
9 papers that are picked up by several press clip
10 agencies and community based newsletters and other
11 professional journals for inclusion in their own
12 newsletters.
13 In closing, I'd like to mention that we
14 are aware of some efforts to enroll prisoners as
15 subjects in clinical trials, but we are not aware of
16 any clinical trials currently ongoing for the
17 treatment of AIDS or HIV related diseases that
18 involve prisoners either individually or as a group.
19 Thank you.
20 DR. OSBORNE: Thank you for that
21 exceptionally clear and concise testimony, it's very
22 helpful.
23 MR. JONES: Thank you. It's a pleasure to
24 have this second time around with the Commission, and
25 I'd like to just for the record to point out that

2 while I'm here with the support and the blessings of
3 my current employer, Macro Systems, I'm actually, my
4 comments are coming more from my position as board
5 co-chair of the National Lawyers Guild's AIDS network
6 and the Washington Correctional Foundation.
7 The last time I spoke before the
8 Commission, I shared with you that I was affected by
9 AIDS in many ways, and at that point I had stated
10 that I had just recently discovered that I had a
11 daughter that was infected by learning also that my
12 grandson was impacted, and as of 5:30 this morning,
13 my grandson died, and so I probably may sound a
14 little disjointed and sort of an emotional wreck, but
15 I made a commitment to be here because I wanted to
16 make some statements and some contributions to this
17 important issue of mine.
18 One of my recommendations would be in the
19 future that we besides support for slides, if we
20 could have support for other ways of presenting
21 material. I had really wanted very much to share a
22 video that has been made by a community group of
23 volunteers called the Boheka Group, and it's a video
24 called "A Will To Live." It's the opposite, if
25 you've ever heard of "A Bad Way To Die," and if I see

2 that movie one more time, I will puke.
3 And I point that out, because one of my
4 recommendations is that we do a better job of
5 monitoring the quality of education presentations and
6 materials that is being presented to persons who are
7 incarcerated as well as correctional officers, and
8 I'm often apalled by persons who gloat about
9 education that's happening, and I immediately say,
10 but what's the quality of that education?
11 If you had been able to see this video,
12 you would have seen persons who are ex-offenders,
13 recovering addicts, former prostitutes, persons who
14 had been involved in adverse behavior sharing with
15 you some of their fear, trust--some of their fears
16 about clinical trials and issues of HIV and AIDS,
17 some of the trust factors that they have concern
18 about, and some of their hope for the future.
19 So I'm hoping, I will make a commitment to
20 try to make this available to the Commission. It is
21 currently still being developed. There is both a
22 male and a female version. I bought with me the
23 female version, but I will try to make both available
24 to you.
25 DR. OSBORNE: Thank you, we appreciate

2 that very much.

3 MR. JONES: And again, I am privileged to

4 have this opportunity to share my perspective

5 regarding inmate access to clinical research trials,

6 not because I am a physician or an academian of any

7 university, but because I am an ex-offender who is

8 committed to being a voice for my brothers and

9 sisters who are behind bars in coping with this

10 disease we call AIDS and HIV disease, and having

11 several times having served the time, I can assure

12 you that sex among and between men, that sex among

13 and between women and sex between men and women and

14 sex between prison official and arrestees and

15 detainees is very much the norm for some, an

16 occasional threat or treat for others, and a source

17 of coersion for others, and as a recovering addict, I

18 can also say from experience that injection drug use

19 is also a norm for many men, women and youth in

20 prison jails and detention centers, and because of

21 these factors, I find it ironic that some would

22 advocate for clinical trials in prisons when we have

23 yet to seriously address the needs for drug

24 rehabilitation in prison, the need for job skills

25 programs in prison, the need for developing coping

2 skills of parenting relationships and handling
3 day-to-day stress and the need for educational
4 programs which include AIDS education.
5 Remembering the historical abuse and use
6 of experimental drugs in prisons in years gone by and
7 acknowledging that to the same extent that racial and
8 ethnic minorities have been disproportionately
9 impacted by a range of medical diseases and social
10 problems and a lack of access to medical care, I
11 believe that incarcerated persons in federal and
12 state prisons and county and city detention centers
13 and jails should not be considered for Phase 1 or
14 Phase 2 of drug clinical trials, trials in which we
15 are not sure of toxicity levels and trials in which
16 placebos are used.
17 However, I do recommend that incarcerated
18 persons with AIDS and incarcerated persons who are
19 HIV positive have access to Phase 3 of drug clinical
20 trials. However, availability of drug clinical
21 trials to persons in any institutionalized settings,
22 whether they be prisons and jails or mental hospitals
23 or residential drug treatment programs or any branch
24 of the military services, should be monitored much
25 closer than drug clinical trials offered to persons

2 who can truly make choices.

3 Drug clinical trials should take into
4 consideration the type of facility, whether it's
5 federal, state, county or city; the length of stay of
6 the individual; the quality of medical care and
7 services available to those persons; the emotional
8 and psycho-social support available to persons on the
9 clinical trial. Follow-through and partnership
10 relationships with medical and AIDS service providers
11 upon release should be explored, and we should ask
12 ourselves if the drug clinical trials are offered to
13 women as well as men, to persons with history of
14 addiction and without regard to the offense committed
15 by the individual.

16 And we should ask ourselves if the person
17 is transferred or released, can that person continue
18 in the clinical trial program, and if the drug proves
19 effective can the arrestee continue medication
20 without cost and will the participation in a drug
21 clinical trial affect their options for release.

22 We should also be exploring issues of
23 testing, we should also be exploring the issues of
24 education level and the ability of the person who is
25 incarcerated to actually understand the potential

2 impact of the drugs on their immune system.

3 We should be talking about antiviral
4 therapy and options, not just AZT, but ddI and should
5 be looking down the road at other potential drugs
6 that may become available at some time. We should
7 recognize that what is written as policy versus what
8 is implemented as a reality are often not in
9 agreement, and we should recognize the weakness of
10 medical facilities at prisons and detention centers
11 in terms of low budget, in terms of being
12 understaffed and in terms of often the medical
13 personnel are not up to date on current medical
14 protocol.

15 Often the medical facilities are but mere
16 first aid stations with subcontracts to city or
17 county general hospitals.

18 We need to recognize and to validate the
19 role of volunteers from community based AIDS service
20 organizations, and encourage them to continue to work
21 with correctional facilities, and I think our
22 testimony from an organization like ACE is an example
23 of how that can work.

24 We need to look at the reality of access
25 to quality health care when individuals are released

2 from the correctional facility, and the options and
3 choices of participants in medical intervention,
4 medical care and medical follow- through.
5 We should not be too shocked over the
6 reality of segregation of housing of individuals when
7 we recognize that in the penal system that women are
8 segregated from men, that blacks, Hispanics, Asians,
9 Native Americans and whites often are segregated,
10 either intentionally by the system or segregate
11 themselves.
12 We should not be surprised when we
13 recognize that gays are often placed in one unit and
14 non-gays in another unit, that we have a forensic
15 unit and a general population, we have protective
16 custody, so we should not have such great shock that
17 now we're talking about AIDS units.
18 There is a strong need and often a
19 minimizing of the need for psycho-social support and
20 I'd like to conclude my comments by pointing out that
21 we really seriously need to give far more attention
22 and respect to the psycho-social implications of
23 individuals who are reaching out for help, reaching
24 out for a will and a reason to survive, and often
25 you're talking about a population that if someone

2 wearing a white jacket or someone says, "I'm from the
3 medical department and you should test or you should
4 try this particular drug," they don't often
5 understand the implications of all of that and we
6 need to take into account those issues.
7 Thank you.
8 DR. OSBORNE: Thank you very much and
9 thank you for taking time with us in an especially
10 difficult time in your life.
11 Any questions?
12 DR. DesJARLAIS: This is I guess mostly
13 for Bob and Ann, but with respect to doing serious
14 research within a prison setting, research that is
15 not just being done so that you can get a drug to
16 somebody who needs the drug, but research with the
17 idea that you would be publishing the results, I know
18 one of the biggest difficulties I had to face when I
19 thought about doing research in prison is how would I
20 be able to publish the results of a study when I knew
21 that there was no way I could guarantee that the
22 subjects were being treated ethically and humanely
23 with respect to basic medical care and with respect
24 to particular AIDS issues, such as education,
25 preventing reinfection, that it would be foolish to

9

2 send off an article to a medical journal saying these
3 are the results of the drugs in a group of people
4 that was not getting basic medical treatment for the
5 complexity of the disease like HIV infection, that
6 unless I was going to be able to find some way of
7 guaranteeing that they really would be getting good
8 health care, that there would be some protection
9 against reinfection, that their psycho-social needs
10 around counseling for the infection and such were
11 going to be met, collecting the data is not going to
12 lead to the research outcome of getting the stuff
13 published.
14 I would just like your comments on that.
15 DR. LEVINE: Well, first, I can respond
16 just out of what are the rules, and no medical
17 journal requires that you be working in an ideal
18 setting. All the medical journals and scientific
19 journals will require of you is that you show that an
20 IRB approved it. Now, IRB's approve research that's
21 done in less than ideal settings all the time. But
22 now, to take your question--I don't want to just set
23 your question aside, Don, with a technicality.
24 If you look at quality research being done
25 in prisons, in your own field, there was at

2 Lexington, Kentucky very high quality work being done
3 on the addictive potential of new analgesic drugs and
4 they were doing the research on people who had been
5 addicted to narcotics and who were at least not using
6 narcotics at the time they were doing it.
7 One of the first things that happened,
8 even before there were regulations, when the National
9 Commission was contemplating putting restrictions on
10 research activities were there were drugs that were
11 not designed to be of benefit to the patients, they
12 just left, they moved to Baltimore City Hospital.
13 They're doing the same thing, but it's not in the
14 prison, so that they're not getting the sort of grief
15 that they expected to receive while working in the
16 prison system.
17 Now, the bulk of the research that was
18 done in prisons was not the sort where the ultimate
19 target was publication, it was Phase 1 drug studies.
20 The ultimate target there is to submit it to the FDA.
21 There was always reason to question the validity of
22 it, not just on ethical grounds. I mean, the
23 presupposition of Phase 1 testing is that the only
24 drug the people are taking is the drug you're giving
25 to them, but many people interviewing prisoners, even

2 in my own state in Connecticut, found they were
3 taking all kinds of drugs and very often not taking
4 the drugs that they were being asked to take as part
5 of a study. They were sharing the drugs, they were
6 getting together and pooling their urine, you know,
7 so they find a little bit of drug in every urine
8 sample.

9 I'm not talking about ethics, I'm talking
10 about pragmatic concerns.

11 I must take exception to one statement
12 that you made, if I will. The reason to be concerned
13 about doing Phase 1 drug studies in prisons has
14 nothing whatever to do with safety. There was that
15 extensive study by Sarah Fenitiz and their conclusion
16 back in the late '70's where they looked at
17 two-thirds of a million prisoner days of Phase 1 drug
18 exposure, and with the most relaxed criteria for
19 identifying what they call a clinically significant
20 event, they only found 28 events. There was no
21 permanent disability. There were two highly
22 questionable cases of temporary disability. The only
23 prisoner who died, died in his sleep while taking a
24 placebo, and this, mind you, is not a placebo
25 controlled trial, this is Phase 1 trial where nobody

2 is supposed to get any benefit.

3 So when you talk about the bad history of

4 research in prison, what we're not talking about is

5 drug research. If you calculate the dangers of

6 getting injured in a Phase 1 drug study, I know I'm

7 going on too long, but one insurance company that

8 tried to set up no fault Workers' Compensation

9 insurance for non-prisoners in Phase 1 drug studies

10 came out with insurance premiums that were exactly

11 the same as those they paid for the secretaries

12 working in the institution's offices.

13 MR. JONES: I would just like to make a

14 quick response. My concern is not only in terms of

15 what I still strongly feel could be abuse in terms of

16 Phase 1 and Phase 2, but also particularly

17 considered.

18 Considering that there's a

19 disproportionate number of persons from communities

20 of color who are incarcerated, and every single one

21 of these racial ethnic groups have a history of

22 having--I mean, whether we talk about Tuskegee

23 syphilis study or in Puerto Rico with the birth

24 control pill or what have you, the combined history

25 of that gives us a collective reason as a community

2 of people to be concerned, and to be reserved, so my
3 concern is, if we do not--when you're talking about a
4 community or a population in which coersion is often
5 part of the method that is used to get people to
6 participate, and if the individual says no, that you
7 are punished, I mean, having been incarcerated, I
8 know if someone is supposed to take medication and
9 they say, "No, I don't want the medication," then you
10 are punished, sometimes subtle, sometimes blatant.
11 So that's my concern.

12 Now, I could probably be talked out of
13 that, but it would have to work through, for me would
14 be the trust factor, and what I said in my testimony
15 is that if we are going to do clinical trials, I
16 think there's a great deal more monitoring that would
17 have to be done with those than we would do with the
18 general population.

19 DR. DesJARLAIS: I just want to make one
20 point about different types of research. Phase 1
21 clinical trials, trying out psychoactive drugs for a
22 short period of time can relatively easily be done in
23 prisons, because you're basically working with
24 otherwise healthy people. When you're dealing with
25 Phase 3 clinical trials or trying to really do

2 research with people who have moderate to advanced
3 stage HIV infection, then you have to really deal
4 with all those other questions of are they getting
5 adequate medical care, are they getting adequate
6 psycho-social care and that's where I see you would
7 have big problems convincing a reviewer that your
8 research should be published, because you were
9 providing ethical treatment to the research subjects
10 and I know many people who would say regardless of
11 the scientific findings, if I knew subjects were not
12 receiving basic, compassionate, adequate medical
13 care, the review would be quite negative.
14 DR. OSBORNE: I have a problem here. I've
15 already reduced the length of our break to five
16 minutes, in order to try and get through all of the
17 people who we want to hear from today and who have
18 taken the trouble to come, so I do have two what I
19 hope to be very, very brief questions from Harlon and
20 Jim Allen.
21 If they're comments, don't make it. If
22 they're questions, brief.
23 COMMISSIONER DALTON: Bob Levine, you were
24 just spared by that, so I want to speak to Dr. Sharp
25 and Mr. Jones. I'll pretend this is a question.

2 I want to thank you both for the care that
3 you took in structuring your comments. There is a
4 very difficult balance, it seems to me, between the
5 need to include inmates in clinical trials with
6 respect to HIV, because it's a form of treatment,
7 frankly, and at the same time the very real problem
8 of not only historical problem of abuses occurring
9 and I thought you both were wonderfully sensitive.
10 I wanted to ask Dr. Sharp just what you
11 meant in your testimony by saying we should consider
12 the issues raised by the Prisoners Rights League, or
13 at least give us a reference to where that can be
14 detailed somewhat more fully?
15 DR. SHARP: Those were included in a panel
16 discussion which in fact has been published, run by
17 Nancy Dubler, and Dr. Levine was present two years
18 ago in 1988 in New York. I can make sure that you
19 have a copy of it. It addressed specifically the
20 issues of clinical trials in prisoners, and
21 prisoners--Legal Services was concerned that in fact
22 certain issues that could result in coersion, were in
23 fact looked at and dealt with, but I will make sure
24 that you get a copy of that.
25 I just wanted to make two comments:

2 Number one, I feel very strongly that clinical trials
3 should not be designed solely for prisoners.
4 COMMISSIONER DALTON: You said that in
5 your testimony, I appreciate that.
6 DR. SHARP: I think that really needs to
7 be emphasized, and the other issue is that about
8 guaranteeing health care or appropriate health care,
9 I think we know that, we've learned in the course of
10 this epidemic that clinical trials do in fact provide
11 better health care to individuals, that there is a
12 plus for being admitted to a clinical trial, and that
13 if you enroll a community patient in New York City in
14 a clinical trial, you in fact take over their health
15 care, so the same goes with prisoners.
16 We did that both at Albany and St.
17 Clare's, we had inmates involved in clinical trials,
18 our patients, and I don't know that I could say that
19 living in the South Bronx today is any better
20 supportive atmosphere than in certain of our prisons.
21 COMMISSIONER DALTON: I had a question,
22 but basically I would like for you two to get
23 together and see what between the two of you come up
24 with and I would like to see the product and she'll
25 pay for it.

2 DR. OSBORNE: Very briefly, Jim, because
3 we are very late.
4 COMMISSIONER J. ALLEN: Question for Dr.
5 Sharp and Ms. Graham.
6 With regard to a patient like Mr. F, who
7 needs the Fluconozale for treatment of cryptoccal
8 meningitis, shouldn't a drug like that be available
9 in a circumstance like this under compassionate
10 release? Now, of all the physicians who we've heard
11 testimony from in the last day and a half, I have not
12 heard one of them talk about compassionate release
13 use of investigational drugs.
14 DR. OSBORNE: You better talk about
15 compassionate use, rather than compassionate release.
16 Those are different matters going on.
17 COMMISSIONER J. ALLEN: Compassionate use
18 of investigational therapies. It seems to me that
19 particularly for a drug like Fluconozale is really
20 the best way to go rather than doing a clinical
21 trial.
22 DR. SHARP: Well, as a matter of fact, in
23 that particular instance, we were able to get
24 Fluconozale through compassionate use. But I think
25 what you need to understand is that despite the fact

2 that the FDA does not prohibit clinical trials in
3 inmate populations with certain restrictions, that
4 the word out there in the streets and in the medical
5 centers is that in fact prisoners are excluded from
6 clinical trials, so when I tried to convince my
7 bosses at Albany Med that this individual should be
8 put on Fluconozale for a compassionate--it took a lot
9 of doing, so I think that the purpose here is to sort
10 of get the word out, and ultimately you would like to
11 be able not to always have to rely on compassionate
12 use.
13 There are other indications, again, with
14 this individual who has since, he just recently died,
15 he was getting his Bachelor's degree in the prison
16 system, and in addition to defending the toxicity to
17 Amphotericin, as you know Amphotericin is an
18 intravenous drug requiring an indwelling catheter.
19 When he had the indwelling catheter, he was in a
20 particular risk and therefore was not able to go out
21 in general population, although physically he was
22 completely able to, but you can imagine pulling the
23 catheter out, so he was proscribed from attending his
24 classes until, fortunately for him, he developed the
25 toxicity to Amphotericin and we were able to give him

2 compassionate use Fluconozale. He took the catheter
3 out, went and got his Bachelor's degree in prison.
4 DR. OSBORNE: Thank you very much for your
5 important testimony, it's really very provocative.
6 I would ask the next panel to join us to
7 talk about HIV AIDS education.
8 While they are joining us, I think I'll
9 beg the question, Karen, there's a public comment
10 interval scheduled for 5:00. Could I ask that anyone
11 who desires to make three minutes of public comment
12 per person contact Karen Porter and let her know so
13 we will be able to anticipate those who would like to
14 speak.
15 Welcome, and thank you for your patience.
16 As you know, we're running a little late, but we're
17 eager to receive your comments.
18 MR. MOORE: Good afternoon, I'll try to be
19 very brief. A lot of things that I wanted to say
20 have already been touched on.
21 I'd like to start off by just reading
22 through a set of recommendations and then I'll touch
23 on some of the points that are in my testimony.
24 Health education and risk reduction
25 programs taught by skilled health educators should be

2 accessible to all residents of federal, state and
3 local prisons and jails to make sure they have the
4 information and resources to protect their health.
5 AIDS education programs developed
6 specifically for correctional social service and
7 medical staff should be mandatory and regularly
8 updated in all systems.
9 Correctional systems must be encouraged to
10 work cooperatively with community based AIDS service
11 organizations in providing support services and
12 counseling to bridge the gap between jails and the
13 community and provide followup services to inmates as
14 they return to the community.
15 Counseling and HIV antibody testing for
16 all inmates should be available on a voluntary and
17 confidential basis.

12

18 Comprehensive compassional medical
19 management must be provided for all inmates,
20 including the range of HIV positive residents from
21 asymptomatic to critically ill.
22 Custody and parole decisions must not be
23 made on the basis of HIV antibody status.
24 Prisons must establish clear policies to
25 guard against AIDS-related discrimination towards

2 staff and residents.

3 HIV positive residents must have full
4 access to educational, vocational, drug treatment and
5 all other institutional services.

6 Condom distribution should be a part of an
7 overall health promotion and AIDS prevention effort
8 in all correctional systems.

9 Correctional administrators must develop
10 policies that assure universal precautions are
11 integrated into the institutional procedures to limit
12 the health risk to staff and residents and. Lastly,
13 medical records; it is important all residents,
14 including those infected with HIV, should be managed
15 in a fashion that recognizes and preserves their
16 confidentiality.

17 Prisons and jails present special
18 challenges and a special set of opportunities to
19 those of us who are committed to controlling the
20 spread of HIV infection and meeting the service needs
21 of residents with HIV infection. The Philadelphia
22 Department of Health through its AIDS activities
23 coordinating office and the Philadelphia prison
24 system over the past several years have been working
25 together to develop appropriate and compassionate

2 responses in the issues and problems raised by the
3 AIDS epidemic.
4 Clear, practical policies that address the
5 needs and rights of both inmates and correctional
6 staff are central to this effort. Balanced policies
7 must view inmates, with or without known medical
8 problems, as individuals with the right to health
9 care, confidentiality and information about their
10 health and health care.
11 Early on in the epidemic, many of us
12 naively acted on the assumption that if we just
13 informed people about the danger, they would change
14 their behavior. For some that may have been enough.
15 For too many, the message needs to be repeated,
16 amplified and expanded. Education must help people
17 begin a process, the end point of which is long-term
18 behavioral change.
19 Risk reduction can only occur when
20 education goes beyond sharing information and helps
21 find ways to help people internalize the need for
22 change. We can no longer let the widespread
23 sentiment that AIDS is someone else's disease go
24 unchallenged. Workshops must help individuals
25 develop personal skills to implement responsibile

2 health maintaining lifestyles. This process can only
3 be effective if its responds to the cultural and
4 social norms of the target audience.
5 Prisons and jails are a particularly
6 usually invisible subset of American society. The
7 scale of American corrections and its peculiar
8 demographics combine to create opportunities to reach
9 large numbers of high risk individuals who are
10 unlikely to participate in health education forums in
11 the community.
12 The Sentencing Project in its 1990 report
13 points out the numbing fact that 23 percent of black
14 men between the age of 20 and 29 are under the
15 control of criminal justice systems. This compares
16 to 6.2 percent for white men, 10.4 percent for
17 Hispanic men and 2.71 percent and 1.8 respectively
18 for black, white and Hispanic women of the same age.
19 The scale is massive. According to the Bureau of
20 Justice Statistics, there were 9.7 million admissions
21 to local jails in the past twelve months--in the
22 twelve months ending in June 30, 1988. We must also
23 note that in the same period, 9.6 million men and
24 women were returned to our communities.
25 I think it's important to note that a lot

2 of our focus today has been on the role of state and
3 federal systems, and in terms of education, one of
4 the most important targets must be that revolving
5 door that sees tremendous numbers of people who will
6 be moving directly back into the community.
7 American prisons and jails hold more than
8 a million men and women at any given point.
9 Overwhelmingly, prisons are filled with minority and
10 poor people and some of the points here I'll skip
11 over, but I would like to notes that education
12 services must focus on the special needs of the
13 demographic group who ends up in prison, and we must
14 also note that women have special needs, and the
15 programs must be developed specifically for them. We
16 can no longer take literature and programs that are
17 designed for a general community audience and assume
18 that that material will be effective in a
19 correctional setting. Painting the face on a
20 brochure black does not create a minority focus.
13
21 AIDS education must be more than an
22 explanation of modes of transmission and a "just say
23 no"-styled admonishment to abstain. We must not only
24 deliver facts, but we must also be sure that the
25 message is being heard.

2 Our mission has at it's core the goal of
3 changing behavior and fostering responsible decision
4 making. The internalization of the link between
5 behavior and health is central to this effort. No
6 AIDS education program can be successful in the long
7 run if it does not foster this understanding.
8 It must also present specific skill
9 building workshops that underscore the health and
10 behavior link and give people tangible tools and
11 strategies that can be drawn on in the real world as
12 they make attempts to implement risk reduction.
13 Staff education must also respond to the
14 needs and concerns of all prison employees. Training
15 must be customized to the job needs of each staff
16 group and regularly updated. Effective staff
17 education is the most essential step in allowing calm
18 and compassionate implementation of policies without
19 undue fears and resistance that accompany a lack of
20 information.
21 The importance of staff education is
22 underscored by virtually every major group from the
23 ACA to the ABC to, you name it, there seems to be an
24 overall clear consensus that we must provide
25 education to staff as the beginning point to allow

2 systems to begin to change their nature.

3 DR. OSBORNE: Let me ask if you could sort

4 of pick up the high spots in the remainder of your

5 testimony, because we'll certainly be looking at it

6 closely as well.

7 MR. MOORE: The challenge of prisons and

8 AIDS is enormous and it is clear that the consequence

9 of not meeting the challenge is unacceptable. There

10 are currently a broad range of responses, a patchwork

11 of programs across the nation responding to the

12 particular needs and limitations of its setting.

13 The local response must continue, but

14 national guidelines and support must be greatly

15 expanded.

16 I'll skip ahead to save time.

17 Let me note that prisons by their nature

18 are slow to change. Health care and health education

19 are not their primary focus. We're a system that is

20 being overwhelmed with sheer numbers, systems that

21 were designed with health care only as an

22 afterthought, and now are typically seeing five to

23 ten percent of their population being in a situation

24 where they need extensive, ongoing medical management

25 and if we're to respond not only to people with AIDS,

2 but to the asymptomatic population, we're looking at
3 unprecedented challenges to correctional medical
4 systems.
5 Currently in Philadelphia about 5 percent
6 of our residents are HIV positive. As I said, the
7 challenge to the medical service is unprecedented and
8 it is also clear that we must see this as a mandate
9 to educators, since that is the only known factor
10 that can stem the tide of this controllable epidemic.
11 Thank you.
12 DR. OSBORNE: Thank you very much, we
13 appreciate it and we'll read--the Commission is quite
14 good about reading the testimony that we're given in
15 addition, so I'm sorry to have to move things along,
16 but I do appreciate it.
17 MS. LETTS: Hi, my name is Sharon A Letts,
18 I've been providing AIDS education in the
19 institutions in Delaware since 1987. Delaware like
20 Rhode Island is a combined jail and prison system, so
21 all of our institutions have both sentenced and
22 pretrial prisoners in there. We have one female
23 institution that holds 170 women.
24 Back in 1985, we had our first prisoner
25 die of AIDS. His name was Ross Black. He had a

2 reported 38 sexual contacts while in the institution.
3 At that point, that is when we all knew that the fear
4 was starting, and it hit big time in our
5 institutions, because there was no education up to
6 that point and no one really knew what was going on.
7 Since that point, nevertheless, in the six years that
8 I've been working in the institutions, I've been
9 working with men and women who have been watching
10 their friends and family die and have had lots of
11 trouble getting access to information for themselves
12 and friends and families, which is why we started to
13 do this, because this isn't really in our realm.
14 I started doing AIDS classes, as I said,
15 in 1987, and I would speak before the class and I
16 would do what we call the basic AIDS 101 and one of
17 the things that I realized was that I could give them
18 all the facts and I could give them all the
19 information they needed to do what they needed to do,
20 but I couldn't tell them about what their lifestyle
21 was like, I couldn't say to them, "These are the
22 risky things that you're doing," because I had no
23 idea. I came from the suburbs, and that is
24 where--yes, I came from the suburbs my mother kept me
25 in the closet until I was 18 and then I went to

14

2 college, so what happened is I decided I was not the
3 appropriate person who should do education, it should
4 be the prisoners themselves.
5 I went to the Key Program, which is a
6 hardcore therapeutic community for heroin and cocaine
7 addicts, and started to educate three of the men
8 there to provide the education in the institution.
9 And I thought when I walked in to start teaching them
10 was I was going to be the teacher and they would be
11 the student, and what happened was I ended up being
12 the student learning about things, about their
13 lifestyles and what they went through.
14 When they started doing the classes, I
15 also noticed a different thing between what happened
16 when I did education and when they did it. When I
17 did classes they were classes. When they did
18 education, they were dialogues, they talked to them.
19 A lot of those people in those classes were people
20 they knew on the street and run with, people they
21 housed with in the institutions, and they knew what
22 those people were doing, too, so they couldn't say,
23 "No, no, not me," because they said, "Yes, yes, you,
24 I saw you," okay? So it was a lot more like that.
25 Where I talked about condoms and clean

2 works, they talked about cookers and condoms and
3 boosting and trading sex for the pipe and all sorts
4 of stuff that I never heard about before, and they
5 had that dialogue that went back and forth.
6 The other thing that I think is really
7 amazing for the men and women who were involved in
8 our education, and we do do it, right now we have
9 four institutions we're planning on doing it in,
10 we're in three and we're working on the fourth, is
11 the overwhelming sense of accomplishment and dignity
12 that we give our educators, because for the first
13 time in their lives they're doing something which
14 they never planned on doing, which is doing public
15 speaking and an education class, so there's a great
16 sense of dignity of doing that and also where a lot
17 of them recognized for a lot of their lives that they
18 took from the community, they were giving back.
19 The other part was that they know that
20 they are helping people, they know that they are
21 saving lives, and they care about doing that, so when
22 they go in the classes and say to them, "I care about
23 you, we ran the streets together, I housed with you,
24 I need you to do this because you're going to die if
25 you don't do that," that really comes across in a way

2 that I could never get it to come across, because I'm
3 from the outside and have no idea what's going on
4 with them.
5 Women do have special needs. We have four
6 women educators in the women's prison and they almost
7 do one on one education classes, which is really
8 nice, but they focus a lot more on empowerment.
9 Women have a real problem with being able to say to
10 their male partners, "I want you to use a condom."
11 That's really new for them. They're not used to
12 making those kinds of demands, and standing by them,
13 so a lot of what we do in those classes is talk about
14 empowerment, being assertive, negotiating for safer
15 sex, also talk about the issues that surround
16 pregnancy and also the delivering an HIV positive
17 baby.
18 Ten to twelve percent of the women in the
19 institutions have AIDS. We have a very high
20 infection rate among the women in Delaware who have
21 infection from AIDS. I'm not sure why it's different
22 in other states.
23 The other thing that was, as I stated
24 before that I think is real important is that when
25 you get people who are from the community from which

2 the people who were there come from, is that there
3 are risk behaviors that I wouldn't necessarily touch
4 on, because I don't know that they participate in
5 them, that these people can touch on, the prisoners
6 can talk to them about that.
7 One of the major ones that we had with our
8 education program, especially since it's conducted by
9 inmates, is that our correctional staff is not as
10 well educated as our prisoners are, so they have a
11 tendency to go in and refute what the educators,
12 inmate educators have just told the classes, and
13 that's a huge problem and the need for correctional
14 staff to be educated I can't say enough for.
15 One other thing I want to mention is that
16 we also have another program through the State of
17 Delaware where we have one on one AIDS education
18 counseling for persons who are sentenced to a year or
19 more in prison. That educator is here with me today,
20 Lisa Bojanski. She sees every inmate upon admission
21 and prior to release. She also does regular
22 counseling sessions with HIV infected prisoners.
23 Thank you.
24 DR. OSBORNE: Thank you very much.
25 MR. HARRISON: Thank you.

2 Let me start by briefly telling you a bit
3 about the National Commission on Correctional Health
4 Care and the work we do. Our purpose is to promote
5 provision of adequate medical care in correctional
6 institutions and confinement facilities.
7 Since 1985, the National Commission on
8 Correctional Health Care, I usually refer to us as
9 the National Commission, but you are the National
10 Commission as well, so I'll either say NCCHC or if I
11 don't catch myself, use our whole name.
12 We've been an independent organization, we
13 have developed widely recognized standards for
14 medical care in jails, prisons and juvenile
15 confinement facilities with which many facilities
16 voluntarily comply. I might add that it is not
17 uncommon, there are a number that do comply under
18 court order. In addition, we provide technical
19 assistance and training to health care providers, we
20 conduct research, put on national and regional
21 conferences, publish a quarterly newspaper as well as
22 a scientific journal of prison and jail health.
23 Our organization operates with the support
24 of 31 national professional associations who appoint
25 a member to our board of directors. These

2 organizations include, to name but a few, the
3 American Medical Association, the American Bar
4 Association, American Public Health Association, the
5 National Sheriffs' Association and the Society for
6 Adolescent Medicine.
7 We first addressed the issue of AIDS in
8 jails and prisons at a national conference we held in
9 1981. Since that time, it's been a major topic of
10 discussion at our conferences as well as our
11 publications.
12 I was asked to speak today about education
13 programs for incarcerated youth, which is an area we
14 get involved in. As some of you may know, there are
15 both short and long-term juvenile confinement
16 facilities. There are some 600,000 admissions to
17 juvenile public facilities annually. Well over
18 50,000 juveniles are locked up on any given day. The
19 typical delinquent admitted to a facility is male and
20 over the age of 15 and ethnicity varies widely from
21 area to area, but the majority of juveniles who are
22 in custody are white.
23 While the population of juveniles in the
24 United States as a whole has been going down, the
25 population of juveniles who are locked up has been

2 increasing for the past several years. The increase
3 is widely believed to be attributed to the increase
4 of drug use, and the sentencing by the juvenile
5 courts for drug offenses.

6 In 1989 NCCHC, with funding from the
7 Centers for Disease Control, sent a questionnaire to
8 1400 public and private juvenile confinement
9 facilities in the U.S. to learn more about their AIDS
10 education activities and over one-third of the
11 facilities responded. The average daily population
12 of youth in these facilities was 51 and the average
13 length of stay was 105 days. These facilities
14 reported 14 confirmed AIDS cases and two AIDS-related
15 deaths. 42 percent provided some form of HIV
16 testing, in most cases when it was clinically
17 indicated or requested by the juvenile.

18 We have found that there's a great need
19 for AIDS education programs in juvenile confinement
20 facilities. Many children in custody are known to
21 have engaged in HIV risky behaviors such as
22 intravenous drug use, sharing of needles, multiple
23 sexual partners and prostitution and the sharing of
24 needles for tatooing and ear piercing, which is often
25 part of a gang-related activity.

Most of these children are from dysfunctional families. It is common that they no longer live at home and are not in school. As a result, these children have no formal access to education other than what they will receive while in custody.

I don't know if you know about that there are some kids who are locked up as status offenders. A status offense is something that would not be a crime if committed by an, adult but as a juvenile, for truancy, for example, you can be incarcerated.

The problem is how to take advantage of the time that children are locked up by providing them with important health education information in trying to effect behavior change. They are not particularly receptive. These kids have heard of AIDS, but many have fears and misconceptions and generally suffer from the invincibility that all teenagers feel. A number of them also feel despair and hatred and profess no particular interest in protecting themselves or others.

Most facilities do provide some sort of health education. They do this either through a curriculum brought in by the local school district or

2 they develop one on their own. In many cases the
3 local Health Department is invited into the
4 facilities and plans to add to these programs with
5 their own.
6 Clearly a child in custody for several
7 months presents a perfect opportunity to provide HIV
8 education and possibly the only formal health
9 education the child will ever get, but local school
10 programs and health departments often are not able to
11 communicate effectively with this population. The
12 issues of cultural sensitivity, clear language and
13 open dialogue are even more important for this
14 population than the teenage population in the whole,
15 but they're not typically found in the public school
16 programs used in detention centers and the child will
17 be in custody for only a few weeks before being put
18 on the street presents additional challenges to an
19 overburdened facility. Our office at the National
20 Commission on Correctional Health Care help juvenile
21 facilities in this area.
22 We provide seminars for prevention staff;
23 these are teachers, counselors, health care providers
24 and administrators. The seminars are intense, three
25 day long activities, provided free of charge.

2 Special curricula is developed for both short and
3 long-term facility and these curricula are asked--we
4 get requests from the State Department of Education
5 to provide this curricula to them, because they get
6 also involved, as I was saying, in health education
7 programs in the juvenile facilities.
8 We also do a training of trainers program
9 to--the word "empower" has been used several times
10 today, to empower local staffs of the facilities to
11 train others on their staff throughout the region.
12 In conclusion, let me say that providing
13 health education to incarcerated juveniles is vital.
14 Because of their behaviors these children are some of
15 the most likely in the country to spread the virus.
16 An opportunity exists while these children are
17 confined and, we must use this opportunity to provide
18 education and try to change behaviors.
19 Additional funding would help, but so
20 would the easing of restrictions that school
21 officials feel on the language that may be used to in
22 presenting this information to hi risk youth. To
23 effectively communicate with a street kid, we must
24 speak that child's language. We must better train
25 our counselors and health educators in the facts of

2 HIV infection and how to better educate and effect
3 behavior change in children that are in custody.
4 I've included in here a policy statement
5 that our office has developed on HIV education for
6 incarcerated youth. We also have policies on
7 management of HIV patients and AIDS patients in adult
8 correctional facilities.
9 I'd like to emphasize what I hear from our
10 counselors who do--who are responsible for talking
11 with kids. They are handicapped by the public
12 concern and concern that's been echoed by some
13 members of Congress about what messages we're going
14 to give when we talk about counseling against HIV
15 infection, and I can be euphamistic or I can be
16 blunt, but it's strongly felt that street language
17 has to be used to talk effectively with street kids,
18 and whoever the person is we're going to educate, be
19 they adult or juvenile, I think we need to speak
20 their language and find out what that is, and that's
21 the freedom that our educators seek.
22 DR. OSBORNE: Thank you very much.
23 Mr. Hernandez?
24 MR. HERNANDEZ: Yes, good afternoon, I
25 realize that everybody is tired, it's near the break,

2 I promise I will not bore you, I'll try to entertain
3 you as much as I can. I'll get to some of the points
4 I'm doing in San Antonio.
5 Just to give you an idea of how dedicated
6 I am, and please, I broke my arm at the Bear County
7 Jail, and I've been working non-stop ever since.
8 They took my cast off, it's a real
9 pain to be acting like I'm falling on one side, but
10 I'm sorry, so I promise I'll go real fast.
11 I want to thank you all very much, it's an
12 honor with I, "gracias por la invitacion" to let me
13 be part of this panel and to share with you some of
14 the things that are happening in San Antonio. I know
15 that most of you all heard so many things about
16 bilingual education, what is it, well, I'm here to
17 tell you exactly what is bilingual education.
18 A lot of people think bilingual education
19 is just going to school to master the language. You
20 got to know the people, you got to know the fears,
21 you got to want to care. There's a lot of people
22 that get into this business and say, "I want to be an
23 educator." Well, it takes more than that.
24 You have to have a lot of dedication. You
25 have to suffer with those people to know what really

17

2 their needs are all about.

3 I'm here to share with you what my

4 expectations are with my staff. I'm very, very

5 demanding when it comes to that, because I even do

6 myself education in the jails.

7 Let me tell you one thing. A lot of

8 people think that Mexicanos, Texanos and Chicanos are

9 the same. We're not the same. Texanos are people

10 born and educated in Texas. The majority of these

11 people speak English only, a few might speak Spanish.

12 Chicanos are more authentic than Texanos,

13 they speak English and slang Spanish.

14 Now, Mexicanos, like me, we speak Spanish,

15 okay?

16 So one of the reasons why I'm saying this

17 is because we have to be very careful when we go into

18 the bilingual education. For example, there are

19 words which are double meaning, for example, the word

20 "cojer." It means "to take."

21 But in slang, and pardon my French, it means to

22 screw. So that's why we have to be very careful when

23 we go out and talk to the people in the jail, that we

24 know how to communicate with them and exactly how to

25 relate this information so we will not offend anybody

2 and at the same time they will be receptive to us.
3 It's very important that we get accepted
4 when we go into a jail scenario. I'm sure everybody
5 here knows that. One of the things I've learned, I
6 heard one person, I will not mention names, that I
7 can remember, he told me, "Well, when I go to the
8 jail and I do a jail presentation, I wear a suit and
9 tie." Well, I got a news for you, we don't do that.
10 In our agency we have to go in there, and we become
11 an inmate. The minute we walk into that Bear County
12 facility you become an inmate, and we have been
13 treated, believe me, I have been treated like an
14 inmate sometimes.
15 One time one guard told me, "What are you
16 doing here, you're supposed to be in cell C?"
17 I said, "No, no, you don't understand, I'm
18 here to do education."
19 He said, "Let me see your badge." I show
20 him my badge, he says, "Sir, I'm sorry."
21 So automatically, once you're in there you
22 become a prisoner. So that gives me an idea what
23 it's like to be treated. I want to be treated like
24 they are so I can come outside and I can help them
25 and better deliver what they need.

2 The next thing I want to say is that we
3 start education with the prisoners, right? Well, we
4 need to start doing followup with their families,
5 because these prisoners are going to be coming out
6 and they're going to be coming home and what's going
7 to happen to their wives, girlfriends, or boyfriends
8 or whatever? They're not going to know anything
9 about this, they need to be informed of this
10 information, so we're moving into that area also,
11 slowly but gradually into the family, because a lot
12 of times they're not too receptive about it, but we
13 are working with the people in the jail.
14 One thing I want to share with you, these
15 things are all happening to me on a daily basis.
16 Before you go into the jails, you have to be aware of
17 what materials you're going to be presenting.
18 Everything has to be screened before you go into that
19 place.
20 I have been reprimanded already because I
21 carry things that are not supposed to be taken in a
22 jail.
23 The next thing that I wanted to say is
24 that when you start doing sexual education, when you
25 get down to the explicit part, we have a way of doing

2 it. We have a male and female. The female does the
3 female, so they get down to the basics. We have the
4 males, they do the same thing, too. But a word of
5 caution when you do that, you have to be very careful
6 how explicit you get, because these guys and these
7 girls will do anything to put you on the spot.
8 An example, one time I went to do the jail
9 presentation for the first time and somebody threw
10 and undergarment at my face to see if I got
11 intimidated, but that didn't work. So that sort of
12 thing. So you got to be prepared for scenarios that
13 can happen around you. And I always tell my staff,
14 staff I say, "You have to be receptive and you got to
15 be open to anything, because anything goes in that
16 jail. Once you walk in, anything can go, so if you
17 can't handle this particular scenario, then I'm
18 sorry, you're in the wrong place."
19 Now, I'm coming from a different
20 perspective in this particular panel, I'm coming from
21 a reality perspective, how the people really are in
22 there, because that's what I've been living, and I'm
23 sorry, I'm not trying to be a showcase or being
24 anything, I'm trying to be realistic, what's been
25 happening to me.

2 The next thing I want to say is that we
3 never share any information, any personal
4 information. Sometimes we can't help it, but getting
5 personal with the people, we care, we want to help
6 them out as much as we can, then they start asking
7 favors from you, and it's important we do not get too
8 intimate and personal, because we don't know what
9 we're dealing again.
10 And my time is up and I would like to
11 conclude by saying that the number one key in
12 education in the Hispanic family and anywhere is that
13 you have to respect people and if you respect them,
14 you'll be surprised how receptive and how well
15 received you will be.
16 Thank you very much for this opportunity
17 and I hope I didn't go 150 miles an hour, but that's
18 life.
19 DR. OSBORNE: You did it wonderfully. I
20 particularly like your last point. That's a very
21 important point.
22 MR. HERNANDEZ: Thank you.
23 DR. OSBORNE: I think we have a few
24 minutes for questions before we take our abbreviated
25 break.

2 MS. DIAZ: I just have one. I really
3 wanted to ask Billy Jones this question, maybe he can
4 still answer it from the back because it deals with
5 three of your presentations, being a health educator
6 by training.
7 Do you feel that most of the materials out
8 there now, we've got such a tremendous amount of
9 materials for AIDS education, are suitable or at
10 least adaptable? I'm not talking about painting
11 black faces on pamphlets, but at least adaptable to
12 be used for the use of prison education?
13 Or like what you have there, do people in
14 prisons need to see themselves in the video and
15 illustrations and materials in order to get the HIV
16 message?
17 MR. JONES: For the most part, the
18 materials that I've seen don't make any sense at all
19 in the correctional facilities.
20 The dilemma we have, again, for the most
21 part, is a budget situation. For example, Department
22 of Corrections will often subcontract with some
23 outside agency or will try to adapt materials that
24 have been developed for another very particular
25 population. They often still censor, so if the

2 material was designed for the gay community, the gay
3 male community, even though they want you to target
4 the gay tier or the gay unit, they still don't want
5 you showing little pee-pee's and pubic hairs, and
6 stuff like that, you can't do that.
7 So the thing is that there are several
8 creative ways to do it. One is having the
9 incarcerated population to design materials
10 themselves, and they can design--and this has been
11 done in a number of areas where they design very
12 creative posters and brochures. It needs to talk to
13 what's going on in the correctional facilities, in
14 terms of their concern in that level, as well as what
15 happened before they got there, as well as what may
16 happen once they leave.
17 There are certain situations that are just
18 different. For example, the issue of tatooing is
19 much more of an issue in any--among youth who are
20 detained, it's a bonding process; the issue around
21 drug injection is different and the issues around
22 sexuality is different.
23 I encourage men, for example, to talk
24 about masturbation much more, and I say, that's a
25 perfect setting to talk about getting used to the

2 feel of condoms while you're masturbating, and you
3 could certainly talk about it on that particular
4 level.
5 So the answer to your question is no, for
6 the most part. I've seen some, but for the most
7 part, no.
8 COMMISSIONER DIAZ: I just wanted to
9 follow that up, I know the Board Chair from Maced is
10 here, Jessie Sanchez, and you're a special adviser to
11 CDC, I hope you carry that message to the big CDC.
12 Is that why you developed a special brochure for
13 people in prison, Jessie?
14 MR. SANCHEZ: Yes, it is. We developed a
15 special brochure for two reasons, because, one--we
16 developed a special pamphlet because we find that in
17 our particular situation, about 57 percent of the
18 population in our area is Hispanic, many of them
19 speak no English, many of them even if they do speak
20 English are unable to read or write, so we had to
21 develop materials which are very, very basic, simple
22 English, very, very basic simple Spanish, and our
23 materials have to be both in English and in Spanish,
24 so we have a need for both bilingual education and we
25 have to use a lot of pictures, and so we think that

2 humor is one of the best ways to educate, so what we
3 tried to do is sum up with little cartoons which
4 illustrate the point that's being made on the page,
5 and so that's why we developed the special brochure.
6 MS. DIAZ: Thank you.
7 MR. HERNANDEZ: I would like to say I have
8 a sample packet of the materials, and I'm sure some
9 of the people will be working with Hispanic people,
10 but this is the only one I got, you're free to have
11 it, but I also have business cards that I could
12 share. If you write me, we'll send you a sample
13 packet on the house.
14 MS. LETTS: I also want to say we
15 developed our own brochures, it's not for a special
16 population, but it's done with the development of a
17 special ed program, one for low literacy, basically
18 the facts on this one, what AIDS is and how it's
19 transmitted, and this one is our prevention one which
20 we've gotten a fair amount of flack over, but this is
21 the one they keep, which I'm real pleased to hear, so
22 I have lots of copies if you would like to have one.
23 DR. OSBORNE: Thank you very much.
24 Scott Allen then Diane Ahrens.
25 COMMISSIONER S. ALLEN: One question for

19

2 Mr. Harrison. Do you have as a part of the National
3 Commission on Correctional Health Care a component
4 that delas with research and experimental treatment
5 for prisoners?
6 I know yours is education, but in the
7 Commission itself.
8 MR. HARRISON: Are you asking do we have a
9 policy on that?
10 COMMISSIONER S. ALLEN: Right, an ongoing
11 study perhaps.
12 MR. HARRISON: No, we don't have a study
13 going on. We've addressed the issue, I'm trying to
14 recall if it has been developed into a policy or not.
15 I apologize that I've only been there for three
16 years, so I'm unable to answer. I know we've
17 discussed it. Our policy on testing, prevention, I'm
18 uncertain. I'll find out and get that to you.
19 COMMISSIONER S. ALLEN: Could you send us
20 whatever you have? Thanks.
21 MR. JONES: I've done some advisory work
22 with Lydia Watts through your agency, and basically,
23 most of the correction--none of the correctional--how
24 do I lump them all together, American Correctional
25 Association, National Jail Assocation, et cetera,

2 have not gone beyond brainstorming any developed
3 policies around the drug clinical trial issue.
4 They began within the last year to really
5 discuss the issues. They have pretty much assumed
6 that clinical trials for the incarcerated population
7 was an issue. They've had a hard enough time trying
8 to address testing issues.
9 MR. MOORE: I think another issue in
10 special materials is so much of it is based on this
11 sort of psychology of doom and hopelessness and does
12 not reflect where we actually are in addressing the
13 issues of treatment for HIV positive, particularly
14 for asymptomatic individuals, and that education must
15 keep pace with those advances, and we can't simply
16 sort of have this all or nothing view of what we tell
17 people.
18 We have to bring them along with the
19 changes as they occur and we have to develop
20 materials that give people hope and make them buy
21 into a process of change.
22 COMMISSIONER AHRENS: I have a question
23 and then maybe a comment for Mr. Harrison. I believe
24 you're the only panelist that we're going to hear
25 today that's going to speak to the juvenile issue and

2 I'm glad you're here, I think it's terribly important
3 and a lot of folks we have in prison were probably
4 infected as juveniles.
5 It's a little unclear to me, I feel
6 there's a breach here that I'm missing as to where
7 did you direct your recommendations in terms of
8 education for juveniles in the criminal justice
9 system? To whom are those comments or policies or
10 recommendations, where are they focused?
11 MR. HARRISON: The standards that we've
12 developed are widely recognized as medical standards
13 and should be followed in jails, prisons and juvenile
14 detention facilities, although not all facilities do.
15 Those that feel they do usually come to us and ask to
16 be accredited, that they have met those standards and
17 we have a different set of standards for different
18 groups.
19 They deal only with medical issues, and so
20 it's generally the medical departments that are
21 recommending to whomever, the sheriff or the
22 superintendent or the warden, depending on the type
23 of facility that they go in for that type of
24 certification.
25 COMMISSIONER AHRENS: Just to comment in

2 terms of how you're directing those, in my experience
3 there are two ways of getting at education for
4 juveniles that are in trouble with the law. One is a
5 very directly in terms of either--and most of these
6 are in county facilities or under county
7 jurisdiction, would be through the county boards or
8 the head of the Corrections Department in the county
9 simply mandated that within the facilities operated
10 by the counties that this shall take place, but the
11 other, and it's a little more difficult to get at
12 because there's so many more facilities that counties
13 contract with that house juveniles that have been in
14 trouble or are in trouble with the law, and that can
15 be done through contracts, because we contracted to
16 these facilities to provide this, but within the
17 formulation of the contract you can include a
18 component for relevant culturally sensitive, et
19 cetera, AIDS education, and that then is monitored on
20 a yearly basis.
21 So there are some ways of getting at this
22 and I don't know how much, how specific you get with
23 counties, but it's been my experience that they
24 haven't really thought of these, most of them have
25 not really given much consideration to how you

20

2 implement something like this and I think you could
3 be very useful in helping them think that through.
4 MR. HARRISON: I would just like to
5 comment on that. Thank you very much.
6 We find facilities anxious to get our
7 help. We don't have a problem finding people who
8 want the education in part because there's a fear, in
9 part because they want assistance and in part because
10 we give it free.
11 The juvenile facilities as well as the
12 adult facilities are strapped for funds and any help
13 they can get outside that is free is greatly
14 appreciated. It is a state law in a number of states
15 that students that are confined must get equivalent
16 education to what they would get in the public
17 schools, and in fact, then, the public schools come
18 in and operate a regular school. It's not quite
19 regular, but it is a teacher who may spend some time
20 in a public school and then come in and spend some
21 time in a facility. It happens in some, I won't say
22 most cases, but it isn't an unusual circumstance in a
23 number of states.
24 In other places the facility feels totally
25 in control, all the staff that is in there that deals

2 with the children are employees of the facility
3 itself, and if they have a health education program,
4 it might run anywhere from the gym teacher spending
5 an hour every six months talking about birth control,
6 perhaps, to something that's much more intense, so
7 you do run the gamut, and if I can comment with my
8 experience in juvenile facilities has been similar to
9 what I've seen in adult facilities, and that is the
10 management makes tremendous amount of difference, the
11 executives in charge make a big difference in the
12 type of program. Regardless of what the policies
13 are, regardless of what the laws are, it's the caring
14 and the quality of the leadership that makes a big
15 difference.
16 DR. OSBORNE: That seems to be a very
17 powerful generalization in general, and that I think
18 is several of the kinds of testimony we've heard in
19 the last couple of days would lead to that kind of
20 conclusion, too, to find ways to inspire management.
21 I think at this point we should take a
22 break and try and keep it to as close to ten minutes
23 as we can, quite literally ten minutes. We do need
24 to get back so we can hear either other important
25 witnesses still.

2 (Brief recess.)

3 DR. OSBORNE: Could I get everyone to take
4 their seats, please? If I could ask the participants
5 in the next panel to join each other at the table.

6 Justice Andrias and Scott Burris and Mr.
7 Pottenger. You probably heard, may have heard me say
8 this, but the Commissioners most enjoy especially if
9 there is a written testimony, getting a chance to
10 read that at their leisure, but to use our time
11 together as interactively as possible, so if you
12 could use that as a governing principle in your
13 remarks, and we'll look forward to having the chance
14 to talk back and forth.

15 Justice, please, if you would like to go
16 ahead, I think we need to in the interests of time,
17 people will join us as they can.

18 MR. ANDRIAS: Good afternoon, my name is
19 Richard Andrias, I'm a Justice of the New York State
20 Supreme Court, and I come here to offer possibly a
21 slightly different point of view than some of the
22 litigators or other professionals that you have heard
23 identify the issues and offer solutions.

24 It's obvious to as learned a body as this
25 that the incidence of HIV infection in the

2 correctional population and the broader criminal
3 defendant or arrestee population is high, growing.
4 I've noted in my remarks drawing on NIJ studies and
5 others that it could be frighteningly high and
6 conceivably the majority of people in certain
7 institutions can be infected, and thus the criminal
8 justice system finds itself in a sense in the vortex
9 of the epidemic in some respects.
10 With all respect to my colleagues at the
11 Bar, I have outlined and I want to stress what I
12 think are the limitations on the litigation process.
13 Some points that I didn't mention in there are, first
14 of all, how overburdened the courts are and the kind
15 of attention that even the most weighty matter such
16 as litigation over either substantive or procedural
17 issues such as HIV, how difficult it is to give them
18 the proper attention, and I've listed what may be
19 cliches at this point, but some of the horrors that
20 surround litigation: The delay, the difficulty in
21 effecting a solution, either by a judge in settlement
22 or a jury; the difficulty of litigation; hardening
23 lines between the parties; the difficulty of
24 monitoring even adequate solutions at the end of a
25 long process, and particularly to where courts are

2 supposed to have cases and contraveries before them,
3 people inevitably die during the process, aside from
4 depleting their already greatly depleted resources,
5 so although I am a trial lawyer, retired for the
6 moment, and a trial judge now, I have very little
7 faith in most instances in litigation, except as a
8 last resort, and clearly, Ms. Freeman and her
9 colleagues and others must on occasion bring lawsuits
10 and certainly that's why I'm in business, to resolve
11 disputes.
12 But I think given the issues surrounding
13 this particular problem and the human dimensions of
14 the problem, litigation is in many respects a last
15 resort and alternatively, I think that either proper
16 court guidelines or Bar Association, ABA, or other
17 guidelines are a far more appropriate solution
18 coupled with the education that goes along with the
19 process of drafting the guidelines or rules, and
20 implementing them.
21 It can do a lot of things. First, it can
22 eliminate most lawsuits, particularly in the
23 procedural area, and I cite, summarize the ABA
24 guidelines in the criminal justice area, and I have
25 the Association of the Bar's report with me, which

2 basically critiques the New York attempt at having
3 guidelines. But as I say, you have an educative
4 effect of drafting and then promulgating and working
5 with these guidelines that can reduce enormously
6 litigation, particularly in the procedural areas, and
7 hopefully which will educate the ultimate decision
8 makers, usually judges, and maybe make those cases
9 where there is a substantive issue be litigated a
10 more enlightened result, so I think it's a far more
11 productive avenue.
12 The process is not always easy,
13 particularly in such a system that we have in this
14 country, wher every state, in many instances every
15 county has different judicial systems; different
16 judicial administrators and different lawyers, but I
17 think it's really the only efficient and appropriate
18 way to go, particularly in the area of correctional
19 law and procedure.
20 It's very difficult to monitor even the
21 most enlightened decisions and orders of even the
22 most eminent federal jurists, so whatever the results
23 of some of the litigation that comes up, you can't be
24 behind every sheriff, correctional officer,
25 correctional official, you just can't be there, and I

2 can assure you that it's one thing for a court to
3 issue an order, it's another thing particularly in
4 areas as murky as these, to see that the orders are
5 carried out.
6 In conclusion, I want to stress that I
7 think the most appropriate answer is, since we have
8 in a sense ironically a captive audience, i.e.,
9 people who are probably infected and are also
10 captives of the criminal justice system one way or
11 another, either in jail or under court mandate to
12 come back to face charges, both drug education and
13 education--drug abuse or drug abuse education, drug
14 treatment, whatever it's called, and HIV education is
15 imperative. The difficulty with it is, and I'm sorry
16 I didn't hear all of the prior speakers, I heard one
17 gentleman, the difficulty in New York with colleagues
18 who have tried to fashion some kind of an effective
19 education process, is two-fold.
20 First of all, there's the sensitivity
21 issues that you've talked about and heard about and I
22 am certain it's beyond my expertise, but secondly,
23 usually you have a moving target. In New York, most
24 people after they're arrested and arraigned, although
25 it's an interminably long time if you're an arrestee,

2 it can range from several hours to several days,
3 usually you're released on your own recognizance and
4 therefore you're out ni the community again, so it's
5 only a brief window that the criminal justice system
6 has the person in its clutches, and even where people
7 go to jail pretrial, they are not there for long,
8 statistically. Again, if you're in jail I assume it
9 seems like an eternity, but it isn't statistically
10 long.
11 And third, if you're sentenced to jail,
12 given overcrowding, firstly, there's moving prisoners
13 about and secondly, people aren't in that long today,
14 so even where the most enlightened educational
15 programs are in place, it's difficult to have
16 appropriate coverage, repetition and so on.
17 And particularly, now, with jurisdictions
18 either rescinding or not adopting needle programs,
19 for political and other reasons, and other
20 difficulties with trying to educate an IV drug user
21 population, I think it's an important opportunity for
22 the society to either at arraignments or at that very
23 brief moment when people return to the courts to
24 stress education. Mechanically doing that is
25 something for others to devise. We're working with

2 the Health Department, court administrators and we're
3 going to have a pilot project in New York hopefully
4 this fall. It's not going to be particularly
5 effective, but it's a first step in a mail
6 notification wher every defendant is notified of
7 their court date and it will be hopefully appropriate
8 educational material.
9 Having people physically present in the
10 courts as people go through the arraignment process
11 is costly, difficult and something we haven't been
12 able to achieve yet, but I think it's imperative and
13 it's a cost certainly far less than the health costs
14 that burden our health systems.
15 You can read; I hope that my written
16 materials are somewhat enlightening, and particularly
17 the attachments would probably be far more helpful to
18 you.
19 Thank you.
20 DR. OSBORNE: Thank you very much. If
21 it's all right, we'll have each of you speak seriatim
22 and then have a chance to interact with all of you.
23 MR. BURRIS: The court system has been our
24 friend in the AIDS epidemic for the most part. There
25 have been some exceptions, but by and large I think

2 it's safe to say that federal courts and to a lesser
3 degree state courts have protected the rights of HIV
4 patients to some degree and help how society responds
5 to the epidemic.
6 What I question in my testimony is whether
7 the courts will have the same role in prisons, and I
8 think they won't.
9 I start with the position that HIV
10 infection and the HIV epidemic in prison is for most
11 important purposes pretty much the same as HIV
12 infection outside prison. It's part of the same
13 epidemic, the people are part of the same community
14 where the epidemic is thriving, they're temporarily
15 absent but will be back.
16 Therefore, when I think we want to
17 evaluate or identify what will be a success in
18 dealing with the HIV epidemic in prison, we would use
19 pretty much what we would use in evaluating the HIV
20 epidemic outside of prison. What we are talking
21 about doing outside or actually doing outside ought,
22 unless there is specific reasons that they can't be
23 used inside, indeed be used inside.
24 We look back at the cases that have
25 happened so far in the courts where prisoners have

2 brought claims against prisons for things that they
3 are either not getting in prison or against prison
4 practices that they object to. I'm afraid we see by
5 and large a considerable inattention to medical
6 facts, an unwillingness to be at all on the cutting
7 edge of treatment, an unwillingness to second guess
8 the medical judgment of non-medical prison personnel;
9 in fact, I think an unwillingness to look very
10 closely at the problem at all.

11 I think there are several reasons why
12 courts have refused to accept the challenge to
13 respond appropriately or heavily to AIDS in prisons.
14 First of all, and this is a big one, the law is just
15 not very good. There is a presumption in the law of
16 prisoner rights that prison officials are acting
17 correctly. This sharply distinguishes litigation in
18 prisons from general health law, where in practice,
19 and I think even to a certain degree in doctrine, the
20 presumption that officials are acting appropriately
21 has disappeared.

22 When we have challenges to health actions
23 outside prison, there's generally a lot of attention
24 to whether or not those health actions are generally
25 approved by responsible health officials at a

2 national level and whether they are appropriately
3 being used to address a real problem in a particular
4 instance. That just doesn't happen in prison and you
5 can see that the most ridiculous justifications for
6 action are accepted by federal courts who if the
7 plaintiff were not a prisoner might throw the whole
8 action out.

9 It's also true that prisoners' rights to
10 to medical care in particular are very limited. It
11 is true that unlike other people, people on the
12 outside, prisoners can go to court and say, "I'm not
13 getting a certain level of care and I should be
14 getting it," and they have a legal claim. The
15 standard that the courts use, however, is deliberate
16 indifference to a serious medical need. That
17 standard can be used by judges to enforce good care
18 for AIDS, but it can also be used by judges to deny
19 it. It's simply a set of words, an empty vessel into
20 which judges can put their attitudes and their
21 willingness to intervene.

3

22 I think there are also practical barriers.
23 Justice Andrias has referred to some of them against
24 intervention in prison and against successful HIV
25 suits in general. These cases are very hard to win

2 from an attorney's point of view. A great deal of
3 the cases don't have attorneys who could face that
4 difficulty.

5 The vast majority of the cases we've seen
6 so far have been brought by inmates who had no legal
7 help in preparing the papers. They were dismissed by
8 the court at the earliest available opportunity
9 legally before there was any discovery, simply on the
10 basis of the legal claims made in the papers.

11 That's just not going to work, given the
12 deference that prison officials are due under the
13 current law. The only way to win the case is to get
14 lots and lots of evidence that shows lots and lots of
15 abuse, get a doctor to go through the medical records
16 and point day after day where something wasn't done
17 that should have been done or some grossly negligent,
18 deliberately indifferent act occurred that just
19 cannot be written off as a single isolated event.

20 Prisoners aren't in a position to prove
21 those cases, and if the courts essentially say that
22 deference to the legal discretion of correction
23 officials will be a reason for courts to ignore the
24 factual allegations of abuse of discretion, we're
25 simply going to get nowhere in court.

2 The ACLU will be able to bring a few suits
3 for a few prisoners, but I can tell you in
4 Pennsylvania we have about 71 correctional
5 institutions between counties and the state and I
6 can't bring a case in every one of those
7 institutions, although I can say that a good third of
8 them have serious problems.
9 I think, to conclude, the most important
10 reason that I think we can't count on courts is also
11 one that's really not blameworthy, and that this is a
12 public health problem. I'm an attorney and I'd like
13 to enforce rights, but looking at what's happening in
14 prisons, I see the need for testing programs, I see
15 the need for education programs. These are things
16 that may not even have a legal hook in every
17 instance, and there are things that prisons are not
18 really equipped to do. There are things that even if
19 you ordered a prison to do and you could come up with
20 an order that was enforceable and monitored, you
21 would be ordering the wrong people.
22 Therefore, what I'm recommending to the
23 Commission, that you use your pulpit and your
24 credibility to make a series of recommendations about
25 how AIDS should be handled as a public health problem

2 in the prisons of this country.

3 I think at the very least you need to

4 issue a call for across the board nationwide public

5 health intervention among people with HIV who happen

6 to be in prison. I think it would be even better and

7 more helpful if you actually tried to develop some

8 minimum standards for what an intervention should be,

9 also minimum intervention for what kind of health

10 care should be available. I know this is sometimes

11 difficult to do, but on the other hand, we out there

12 have nothing to point to right now or very little to

13 point to. We don't have any authoritative book to

14 use. We can't talk about national standards in a

15 very effective way.

16 I certainly think also we need to hear

17 something very strongly from you about

18 confidentiality and anti-discrimination. Right now

19 it's very difficult to find a prison that really

20 protects confidentiality, and without confidentiality

21 there's simply a daily invitation to discrimination.

22 We haven't had very good success either in policing

23 that discrimination, because prisons are just not

24 open to us, and it's always a prisoner's word against

25 a guard's.

2 Certainly I think there ought to be some
3 effort to deal with improving access to cutting edge
4 therapies. That's a very difficult area, but I think
5 it's a very appropriate one for the Commission to
6 make recommendations on.
7 I think also we need to get the Centers
8 for Disease Control to come out very strongly for a
9 public health approach to prison HIV, more
10 seroprevalence studies, more efforts to foster the
11 development of programs that will work inside prisons
12 for education and medical care and of course drug
13 abuse treatment is also something that is lacking in
14 prisons.
15 It's all in my papers. I, too, know you
16 can read, but I hope that you will not only just
17 read, but also write and produce something that
18 really can become the centerpiece of a renewed
19 national interest in dealing with this part of the
20 HIV epidemic.
21 DR. OSBORNE: Thanks very much.
4
22 MR. POTTENGER: My name is J. Pottenger,
23 and unlike the two gentlemen on my left, I had the
24 foresight not to give you copies of my testimony, so
25 you're stuck with listening to me. I have given your

2 staff a copy, however.
3 Before I deliver what I planned to say,
4 though, I want to comment briefly on something that
5 Scott Burris just said. He talked about the
6 deliberate indifference standard as an obstacle to
7 the level of medical care in correctional facilities
8 and the federal standards.
9 There's no question, obviously, about
10 that, that's the 8th Amendment Constitutional
11 standard, but that's not necessarily the standard of
12 care that correctional officials and doctors owe to
13 their patients, and I don't want people to forget
14 that there are malpractice levels which are in theory
15 lower and which ought to apply under state law
16 certainly to the level of care that gets delivered
17 inside the correctional facilities, and one way that
18 my office has managed to use that once in the HIV
19 context and once not, was to try and look at prison
20 as a barrier to access to care, and to find a health
21 care provider in the free world who was ready,
22 willing and able to give the care that the prisoner
23 sought to the prisoner, and then the institution
24 obviously denies access to that care, and then the
25 institution is in the awkward position of either

2 having to deliver the care itself or put the person
3 out in the community in a position where he or she
4 can get it.
5 This worked for us in one case for an
6 inmate who wanted ddI treatment for his condition and
7 just this spring for an HIV infected inmate who was
8 in federal prison custody and who wanted access to
9 ddI, his prison doctor recommended it, the people at
10 the institution said we don't give that, so we
11 prepared papers saying, well, we've got somebody on
12 the outside who wants to give him ddI, and it's only
13 by reason of him being incarcerated that he's not
14 getting it, and they ended up releasing him.
15 So I think it's not quite as bleak with
16 that deliberate indifference standard, doesn't have
17 to be quite as bleak with respect to the quality or
18 the level of care that gets delivered. Treating it
19 as a community care problem and a but for access
20 issue is a different way to look at it.
21 Another thing that Scott mentioned, and it
22 was in passing, subtle, but very telling, and that
23 was about deferring to the medical judgment of
24 non-medical personnel. I'm sure you've all heard
25 that.

2 One of the goals I think of anybody who is
3 representing prisoners in this kind of a context
4 ought to be to get them to have access to the medical
5 care personnel, not through screens by custodial
6 personnel, and in Connecticut we're trying to do that
7 in two ways in particular: One, with something of a
8 prod from us, the Department of Correction is
9 exchanging its initial health screen exam, which it
10 gives to every--and Connecticut is a unique state,
11 because the Department of Corrections combines the
12 jails and the prisons, so all the jails are under the
13 authority of the Correction Department as well as the
14 longer term institutions.

15 What that means in practical numbers is
16 that there are about 50,000 inmates, close to 50,000
17 inmates who pass through the Department of Correction
18 in Connecticut each year, even though there are only
19 a few more than 8,000 beds. There's a very high
20 turnover rate, a lot of those people are there for
21 short stays in the jail, but they all get an initial
22 health screen unless they're out within an hour or
23 so, and up until recently those health screens have
24 been performed by custodial rather than medical
25 personnel, and one of the things we're negotiating

2 with the State about is to have all those screens
3 done by so-called medical personnel rather than
4 custodial personnel and that's supposed to do two
5 things:
6 One, it creates a duty of confidentiality,
7 a medical duty of confidentiality, a confidential
8 relationship between the screener and prisoner which
9 doesn't exist otherwise and which may, who knows,
10 there aren't very many secrets in prisons, which may
11 facilitate some of the problems of confidentiality
12 that Scott talked about and it may also result in a
13 heightened capability or competence on the part of
14 screeners so they can pick up when people are
15 suffering symptomology of HIV infection come through
16 the system so they can be spotted at an earlier stage
17 and put on to a faster track toward medical treatment
18 and attention, which is one of the other things we're
19 negotiating with the State about.
20 The other thing we're trying to do to
21 enhance the direct access to medical personnel, is to
22 supplement the normal sick call system with a direct
23 access to medical care in which a prisoner can
24 through use of a locked box make a request to see
25 medical personnel and that box is only open to and

5

2 opened by medical personnel, so an inmate doesn't
3 have to go through a guard or through a custodial
4 person to carry his or her request to get access to
5 the medical department in that fashion.
6 I'm not here to pretend that miracles get
7 worked, but either of those may help some of those
8 concerns.
9 Now, let me get into my planned remarks.
10 My designated topic for this afternoon is
11 the making of HIV AIDS correctional policy through
12 litigation and I agree with the judge that it ain't a
13 good idea, that's my main, first paragraph. It's a
14 chancy undertaking, I don't recommend it.
15 The courts are reluctant to intervene in
16 issues of prison management, even as to life and
17 death issues and HIV AIDS policy is no exception.
18 There's no magic exemption, even for as serious an
19 epidemic as this.
20 That said, unfortunately, there are and
21 there have been, at least in my experience, some
22 situations where litigation is the only way to assert
23 the rights or to try and bring the situation of your
24 client to the attention of somebody who can do
25 something about it, and the two situations or the two

2 generic, I tried to think about a number of cases
3 that we've had in our office, and the two generic
4 situations that I can try and describe are one, where
5 in an individual case the prison bureaucracy for some
6 reason is just not responsive and you're not able to
7 get to somebody who has the wisdom or self protective
8 instincts to deal intelligently with a very serious
9 situation, and so you have to flash some lawsuit
10 papers in front of somebody to get their attention,
11 and the other is when there's a political
12 policy-making paralysis in which the prison
13 administration or the Department of Corrections
14 administration, because of the different concerns and
15 pressures on them, can't do the right thing, even if
16 they will tell you quietly that they would like to do
17 the right thing, and the situation that perhaps
18 illustrates that easily is a problem in Connecticut
19 of confidentiality.
20 We were negotiating with the Department of
21 Corrections for quite some time about trying to
22 enhance confidentiality protections and the
23 Department didn't want to hear from us, and partly
24 they didn't want to hear from us because there was
25 civil legislation pending in the State legislatures

2 and the Governor's cabinet was meeting on this,
3 trying to figure out what their position was and the
4 Department of Corrections was busy lobbying in that
5 forum to try to get as big a gaping hole in the
6 Corrections Department in the protection they could,
7 and didn't want to deal with us, but they also had a
8 problem with their guard's union, who desperately
9 wanted to know who was infected and who was not
10 infected.

11 Connecticut is a good union state, even if
12 it doesn't vote Democratic in presidential elections,
13 and so that element of the correctional system put a
14 lot of pressure on the prison management and prison
15 administration not to make a deal with the civil
16 liberties bar about confidentiality and privacy and
17 so forth, so you're left with a paralysis at the
18 Department of Corrections which can only be resolved
19 through litigation.

20 DR. OSBORNE: Professor Pottenger, I'm
21 happy to tell you our staff was swifter than a
22 speeding bullet in giving us copies of the written
23 testimony. So if you could highlight for us parts we
24 should read deliberately, we want to interact with
25 you as well.

2 MR. POTTENGER: That's great, I was
3 elaborating on it slightly already, but you already
4 knew who I am, then, and you know why I think I know
5 something about this.
6 I described the federal situation before,
7 where the man was trying to get ddI treatment. As I
8 mentioned in the testimony, he got transferred from
9 federal custody into the custody of another state,
10 and I think the problem of release planning and
11 transition planning and I highlight that in my
12 written testimony, is one that really bears
13 attention.
14 Oftentimes records get lost, records get
15 mislaid or nobody pays any attention, and people,
16 that kind of delay is fatal for this population. And
17 so not simply interjurisdictional transfers pursuant
18 to detainers, but even intrajurisdictional transfers,
19 from one jurisdiction to another, present special
20 problems for this population and making sure that the
21 medical information follows the inmate in a way that
22 the medical department is able to make timely
23 intervention and timely monitoring is very important.
6
24 I do want to put on the record some of the
25 good things about the class action that we brought in

2 Connecticut. As you could see from the paper, the
3 Civil Liberties Union and the Yale Clinic represent a
4 statewide class of all prisoners in Connecticut with
5 respect to HIV issues. The suit concerned four
6 different issues: Education and counseling, medical
7 care or treatment and confidentiality. We settled
8 half the case.

9 We settled a year ago the education and
10 counseling part of the dispute, and as a result there
11 is now universal HIV education in the Connecticut
12 prison system, and since it's a unified system, that
13 means everybody who goes to jail in Connecticut and
14 stays a day as part of their orientation in the
15 institution gets some HIV education.

16 The numbers that they gave me the last
17 couple of days are impressive. In the last three
18 months, over 10,000 inmates in Connecticut got HIV
19 education as part of their initial orientation,
20 that's in the last three months and that's on an
21 ongoing basis.

22 Also, pursuant to the settlement, there's
23 been one hundred percent education of the staff in
24 the correctional system, both medical and custodial
25 personnel, and that's on an ongoing basis.

2 Counseling is enhanced and so forth and I gave you
3 some statistics about that.
4 Confidentiality I think is the toughest
5 nut. Like I said, like Scott said, there are no
6 secrets in prison or there are very few and
7 realistically there's also a tradeoff in this kind of
8 a situation, because to the extent that you keep
9 under lock and key and in a very small group the
10 information that an inmate is infected, you perhaps
11 restrict his ability to get special attention and
12 monitoring either through counseling and support
13 groups or through medical care at a more intense and
14 enhanced level, and so it's a tradeoff that one has
15 to recognize right from the outset.
16 That having been said, one thing that this
17 Commission could do is to underscore the importance
18 of confidentiality and to underscore the fact that
19 the people who need to know that somebody is infected
20 with HIV is a lot smaller than prison guards and
21 prison management even think.
22 Personally, I don't understand why the
23 warden needs to know who has HIV in his prison or her
24 prison. I honestly don't. I think the medical
25 department needs to know, and beyond that, it gets

2 pretty hard for me to figure out why anybody needs to
3 know, and the exception that, "Oh, the head of the
4 institution needs to know, and the head of the
5 Department of Corrections needs to know" falls off
6 people's lips relatively quickly and I think without
7 examination.
8 To the extent that it's possible, if this
9 Commission could push the guidelines such that only
10 medical personnel are the ones who know somebody's
11 HIV status, and the information is in their medical
12 file and not reproduced and not spread around in
13 other places or in other fashions, I think that would
14 be the best protection that you can have for
15 confidentiality in an admittedly difficult
16 environment, especially if that's coupled with
17 intense training of the medical care personnel in
18 their confidentiality obligations.
19 They sometimes forget, I think, especially
20 the lower level people. In Connecticut they're
21 called medics, which is a guard who had some training
22 in medical issues, but impressing on the medics that
23 now that they're a medic, they've got professional,
24 quasi-professional, para- professional obligations of
25 confidentiality, can be a step toward trying to

2 enhance to the extent possible some of the
3 protections that we're all concerned about.
4 Thank you.
5 DR. OSBORNE: Well, thank you and thank
6 all three of you for important testimony.
7 Are there any questions from the
8 Commissioners? Larry?
9 COMMISSIONER KESSLER: Mr. Pottenger, I
10 was wondering if you had any sense of what that
11 education is? Is it more than a brochure?
12 MR. POTTENGER: The education that's going
13 on now for the 10,000 inmates? It is. It's a
14 brochure, it's a videotape and it's a live question
15 and answer session. It's a live presenter. It's
16 primarily a videotape with a presenter and that's the
17 orientation. There's also a brochure.
18 Then in addition to that, every
19 institution has a weekly more in depth educational
20 session which is voluntary, but the three components
21 are brochure, videotape and live presentation
22 question and answer.
23 COMMISSIONER KESSLER: Is there any plan
24 for followup six months or a year later?
25 MR. POTTENGER: Only through weekly

2 sessions in the institutions. Unfortunately, given
3 recidivism rates, there's followup in that fashion.
4 For too many of the people who get it the first time,
5 but not--and the program has obviously changed. You
6 don't come into jail a year later and see exactly the
7 same thing that you saw the last time.
8 COMMISSIONER KESSLER: What's the status
9 of condoms in Connecticut?
10 MR. POTTENGER: Our Commissioner is not in
11 favor of condoms.
12 COMMISSIONER J. ALLEN: Two questions:
13 Is there anything the courts might be able
14 to do in terms of the issue of condoms being
15 available in prison? That's something that certainly
16 would be available on the outside.
17 MR. POTTENGER: That's an interesting
18 application of the theory that I spun out for you. I
19 think the fact that it's proscribed behavior in
20 prison, it violates the rules to have sex, suggests
21 that the courts are not going to see it as
22 appropriate for themselves to step in.
23 MR. BURRIS: We've tried to put, the
24 strategy has been to try to take the things that are
25 public health interventions outside and find a way

2 that they become something that a prisoner is
3 entitled to get, so for example education is cast in
4 lawsuits as part of medical care or it can be cast as
5 part of the federally funded prison's anti
6 discrimination obligations.
7 If they don't educate their prisoners
8 about HIV, then there's more discrimination about
9 HIV, so if we find something to put a condom on in
10 prison in terms of the law, then there's a chance of
11 getting them in, but I think the chances are remote.
12 MR. ANDRIAS: New York City jails
13 distribute them, at least on a certain basis,
14 although I don't know why they use them, because
15 there's no sex in prison, apparently. That's the
16 policy, but they are distributed. Why, I don't know.
17 It seems to be contradictory.
18 I don't see the courts getting involved in
19 that particular issue. I just don't--at least in
20 most jurisdictions.
21 I just want to stress one thing, it's not
22 a question, but I didn't get to touch on it except
23 briefly. While you were focusing on the correctional
24 issue, most people don't go to jail in this country
25 and a lot of people don't like that and think it

2 should be the other way around. So we don't,
3 although this is your focus at this session, it
4 shouldn't be the focus necessarily of your overall
5 view.
6 Most people accused of crimes, I think
7 rightly so, are trusted at least under the state
8 systems that they'll come back. Many don't, but that
9 they're supposed to come back, and to suggest that
10 the focus is just on incarcerated or detained people
11 is just being myopic and it's part of the irony of
12 the fear in the court system when the people come--I
13 mean, the people can come out of the audience
14 infected, but God forbid somebody comes out of the
15 pen, if they're infected it's often hysteria, or it
16 used to be it isn't now.
17 If somebody came downtown on the subway
18 and showed up for their case, they're in exactly the
19 same medical situation, and it doesn't cause any
20 concern at all, which has helped us on the education
21 of correctional and what we call court officers here,
22 I guess bailiffs in other places, which are the same
23 people. Some days they're in, some days they're out,
24 we parole them or release them, they come back in on
25 a new case, whatever, it's all the same population in

2 many cases and the problems are the same.

3 It changes when they go into detention,

4 but a lot of issues don't change and the education,

5 if we're talking about ending the epidemic, which is

6 a public health objective, it's the same population,

7 really.

8 COMMISSIONER J. ALLEN: I'd like to follow

9 up with one additional question that I'm going to

10 direct to Mr. Burris, but others can feel free.

11 I'm intrigued with your call for national

12 standards and the implication being that you would

13 take those and could use them, then, through the

14 court systems to try to get implementation if they

15 aren't picked up and otherwise directly implemented.

16 I think that's a marvellous idea, except

17 that with this epidemic, both for public health

18 practice as well as for medical practice, progress is

19 being made so rapidly, and approaches are changing,

20 that by the time we get national standards out to the

21 point that they could be used in the court systems,

22 things are already beginning to change, and I never,

23 I don't see that in a system that depends on

24 stability and being able to take that standard and

25 then over a period of time, usually months, often

2 years, that things are going to be so badly out of
3 date that whatever standards are put in place aren't
4 going to be useful.

5 MR. BURRIS: Well, that's entirely true,
6 except the final part of what you said, which is that
7 they wouldn't be useful. All standards that have
8 been promulgated have more or less quickly gone out
9 of use or become less accurate. On the other hand,
10 if you look the at the AIDS litigation in the last
11 ten years, you'll see that CDC guidelines were
12 enormously influential in determining how courts
13 would behave, for example, when children go to
14 school.

15 Those guidelines have changed over time,
16 they have sometimes been misinterpreted, I believe,
17 or have been less than clear, for example, on the
18 case of whether or not health care workers should be
19 tested as part of their job. Some courts have
20 misinterpreted that.

21 On the other hand, the existence of those
22 guidelines has been the mechanism by which some sort
23 of national standard of public health practice or
24 national understanding of what the best response to
25 AIDS in certain situations should be has worked its

2 way into court. We don't have anything like that,
3 really, in prisons. I mean, there are some prison
4 organizations that have produced guidelines, but by
5 not having special guidelines, for example, on
6 confidentiality in prisons, or on the application of
7 the HIV test in a prison setting, things like that,
8 these are things where there's not going to be a
9 whole lot of change in terms of the medical
10 developments underlying them, but by having only a
11 standard for the quote-unquote general population, we
12 have an immediate out for the ad hoc decision making
13 within prisons.
14 I think that while I want to acknowledge
15 that there is a problem in promulgating more specific
16 guidelines, for example, on medical care, I want to
17 suggest to you that it's nevertheless important to
18 try even if they're useful only for the next three or
19 four years or if they're produced with the caveat
20 that events may change their applicability.
21 Certainly, for example, we have a fight to
22 get regular monitoring of people's T cells after
23 they're identified. I can't imagine in the next five
24 or ten years that it's going to cease to be good
25 practice to give somebody a good physical where

2 they're actually touched by the doctor, and where
3 they get certain x-rays for example for TB, and I'm
4 not even a doctor, so there may be mistakes in here,
5 but what I picked up over the years, certainly where
6 there are T cells being monitored, those things have
7 to happen and when the CDC tells someone in a prison,
8 that you have to do, following certain kinds of
9 things, monitoring, a person has to be evaluated for
10 drugs, among which are currently Pentamadine or AZT,
11 I really think that would have a great impact.
12 It would be much harder for them to say we
13 live up to the American Correctional Association
14 guidelines, we're a certified institution, we do the
15 latest thing, anything FDA approved we approve.
16 It's very non-specific and allows them
17 perhaps more discretion then they always deserve to
18 be able to exercise.
19 MR. ANDRIAS: This isn't an advertisement,
20 and I certainly am very selective about ABA policy
21 myself, but there was a committee set up about two
22 and a half years ago, the ABA house of delegates did
23 pass guidelines on both, well, the issue on
24 criminalization of AIDS, the courtroom setting and
25 correctional setting, which are appended to my

2 testimony.

3 I will say that I don't think they
4 realized what they passed, but the committee had a
5 very broad spectrum, and it was very conservative
6 people, almost Reagan appointees.

7 There are standards. I would like to
8 think they were pushing the standards aggressively.
9 It's not really being done, I'm sad to say. I think
10 although it doesn't go to the detail that's been
11 suggested in the health care area, you would do well
12 to push our standards better than we're doing, so--

13 COMMISSIONER DALTON: Scott, I think in
14 your colloquy with Jim Allen, it became most
15 persuasive when you began talking about specifics and
16 it occurred--I say this advisedly, as you know there
17 are other things I'd rather you be doing with your
18 time, but if you were to work on some minimum
19 standards for treating HIV in prisons as a public
20 health problem, it would give us something to chew
21 on, and maybe with the help of some doctor who can
22 help you, specifically help, so that would be truly
23 helpful.

24 MR. BURRIS: I'll be happy to do it.

25 MR. POTTENGER: We can send you the thing

2 we worked out with Bobby Cohen, who testified earlier
3 today, which is a protocol and sort of time flow
4 chart for what ought to be done when.

5 COMMISSIONER DALTON: That would be
6 terrific. Thank you.

7 Justice Andrias, you're absolutely right
8 that lawyers often tend to be myopic, actually
9 everybody tends to not appreciate the extent to which
10 it's really the criminal justice system short of
11 incarceration where much happens.

12 Scott Burris and I, in the first edition
13 of our book, were myopic in that sense, had the sense
14 to have a chapter added on the criminal justice
15 system. I should have asked you to write the
16 chapter, you would have been superb. But Martha
17 Fields, if she calls you for some real practical
18 advice, will you please talk to her about this? I'm
19 really serious about this.

20 I, too, am a believer in judicial
21 guidelines as being important and effective, both
22 within litigation and after litigation. The problem
23 is, it requires people like you, rather than people
24 like me, to get your colleagues to pass such things
25 or Judge Hennessy in Connecticut, but there aren't

2 enough folk like you around, but there's also the
3 problem of enforcement, and you mention in your
4 written remarks that there needs to be firm
5 implementation and I guess I want to know how can you
6 in fact implement judicially derived guidelines for
7 how judges should behave, how probation officers
8 should behave, how lawyers should behave with respect
9 to HIV in the courtroom.
10 How can you put teeth in those?
11 MR. ANDRIAS: Well, it's a major problem.
12 Judges are independently elected or appointed and for
13 some reason feel that nobody can even suggest what
14 they should do in a lot of instances, and judicial
15 education, unless it comes from the inside, is
16 difficult. We are the worst in a sense of being
17 receptive, because the nature of the position is that
18 while you're there you make decisions, so you assume
19 that you know everything.
20 And I am sad to say there has been
21 judicial education offered to judges; financial,
22 everything taken care of, and you're familiar with
23 one project, but I became consultant informally to
24 another one where nobody was willing to pick it up.
25 It's extremely difficult, so I guess the only answer

2 to that is that people can't get discouraged, and
3 that wherever there's an opening, whether it's at an
4 ABA convention, which was a very shabby turn ut, I
5 must say, where we were put down in the basement and
6 people like your Chair had come to talk to 16,000
7 lawyers and maybe 90 showed up, if we're being
8 charitable.
9 There's no simple answer. Part of
10 that--and John Grissom, the former Chair of the
11 criminal justice section of the ABA, will tell you
12 how horrible it is in the federal system. If you
13 think local and state people are difficult, give
14 somebody life tenure and then try to educate them
15 about something. So with some exceptions, federal
16 judges are not receptive.
17 So for Commissions like yours, which have
18 the imprimatur of the federal executive, it's very
19 important, every time there's an opening, you have to
20 take advantage of it, whether it's traveling and
21 speaking somewhere or--I turned down a trip to Hawaii
22 last year because of my own pressing business, I
23 didn't want to, but those kinds of opportunities,
24 it's very difficult and I have no simple answer.
25 I get periodically and cyclically

2 discouraged in New York. I don't know what it's like
3 to appear before judges when lawyers get depressed,
4 I'm sure they get depressed, it's depressing within
5 the judiciary, because the answer is, oh, we did that
6 last year, we had our session on AIDS. The fact it
7 wasn't mandatory and wasn't followed up on--and
8 again, we also have a moving target, we have people
9 going in and out of the ranks of the judiciary also,
10 so it's a continuing obligation.
11 So I have no real answer to it, I really
12 don't.
13 DR. OSBORNE: Thank you all very much.
14 We've got two additional important
15 witnesses, and so I think we probably need to move
16 on, but we're very grateful for your taking the
17 effort to come join us.
18 I'd like Cathy Potler and Romeo Sanchez to
19 come up, please.
20 Thank you both for joining us, and you
21 probably heard me say ad nauseam if you could make
22 your comments brief, so we have a chance to interact,
23 we'll enjoy that and if you would talk in sequence,
24 and then we can talk with both of you.
25 MS. POTLER: Thanks, it's a pleasure to be

10

2 here today to talk about an often ignored issue,
3 early release for terminally ill prisoners with AIDS.
4 If there's one thing that I want to leave you with,
5 it's the importance that a prestigious organization
6 like the National Commission on AIDS can take in
7 terms of making very specific proposals,
8 recommendations in favor of releasing seriously ill
9 prisoners with AIDS prior to usurping their minimum
10 sentence.
11 There really is no jurisdiction that is
12 really dealing adequately with this issue, and it
13 would be really, really important to have a proposal
14 from you recommending early release.
15 Before I discuss the areas in my
16 testimony, I just want to talk for a moment about who
17 the prisoners are. I'm going to talk specifically
18 about New York, since the organization for which I
19 work has legislative authority to go in and inspect
20 prisons throughout the state and report to the
21 legislature their conditions, and since 1984 we've
22 been focusing on all aspects of the AIDS issue in New
23 York State, and I just want you to be aware that
24 we're talking about prisoners with AIDS, we're
25 talking primarily, perhaps 90 percent of people who

2 are African American and Latino, we're talking
3 primarily about IV drug users, we're talking
4 primarily people who are from New York City and for
5 women, we're talking about women who have died, who
6 have left two children, on an average of two
7 children, and we're also talking about people who
8 have predominantly been convicted of money seeking
9 crimes in relationship to their drug habits.
10 So I just from there want to talk a little
11 bit about the importance of early release of termly
12 ill prisoners, and I'm going to take it from the
13 angle of the family, because I think very often we
14 think of prisoners as being the person who is
15 incarcerated without any other relationship to a a
16 family unit, without any relationship to our
17 community, so I think it's important to talk a little
18 bit about where the family fits in all this.
19 We do run a program where we provide
20 support and referral services to families and friends
21 of prisoners and releasees with HIV or AIDS and one
22 of the issues that comes over and over again to us is
23 how much the family members want to be with the loved
24 one, particularly during--I mean through all stages
25 of the illness, but particularly during the last

2 stages, and many of us know that the relationships
3 have been rather rocky relationships all along the
4 years, but nonetheless, at this time, particularly in
5 the last stage, there's a real push towards
6 reconciliation among many of the prisoners' families
7 and the prisoners themselves, so it's very, very
8 important for the families to be able to have time
9 together before the death of a loved one.
10 And in New York State most of the prisons,
11 we have about 61, I think as of today, most of the
12 prisons are far away from New York City and most of
13 the prisoners' families, practically 90 percent of
14 the prisoners with AIDS are from New York City, so
15 it's really, really difficult for them to be able to
16 make the trip on a regular basis to visit a loved
17 one.
18 And I think it's something that's very
19 difficult for those of us who may not have had this
20 experience to know what it is like. I mean, in New
21 York State, for instance, families arrive at a
22 central location in Manhattan around 10:00, 11:00 at
23 night; they wait for a bus; they travel on the bus
24 the entire night to the next morning; they arrive at
25 the prison around 7, 8:00 in the morning, then wait

2 for often several hours to go through processing
3 until they get an opportunity to visit the person
4 they're visiting, the loved one, and then at 3:00
5 they must leave, be rounded up and put back on a bus
6 that arrives in the early morning of the next day.
7 And that's a really grueling trip. It's a
8 grueling trip for children, it's a grueling trip for
9 grandmothers who we have found to be the caregivers
10 often of the children of the prisoners, and it's just
11 a horrible situation, and it's unfortunate that the
12 families get so short shifted in our system.
13 I just want to bring another example of
14 what happens to families. There's a family reunion
15 program in New York State which enables spouses and
16 parents, children and siblings to come visit a
17 prisoner for almost two days. They spend that time
18 in a trailer on the grounds of the prison and they
19 get to cook together and be together.
20 Well, if you test seropositive in New York
21 State, you are automatically denied that visit. It's
22 a ridiculous policy, it's a policy that to my
23 understanding the Commissioner is not going to budge
24 from at this point, and it actually does, at least
25 with the spousal visit, just the opposite of what it

2 pretends to say that it does, which is prevent
3 transmission.

11

4 The message is all wrong as far as
5 parents, children and siblings as to how HIV is
6 transmitted.
7 I would like to mention and I know you've
8 heard a lot of testimony today in terms of a lack of
9 health care services, of an often sophisticated type
10 of service that's needed, skilled nursing care, where
11 the outside hospitals will not keep prisoners who are
12 at the final stages.
13 I have on more than one occasion sat in a
14 room with a prisoner who basically couldn't move from
15 his bed, couldn't even get a pencil off his night
16 table, who is sitting there doing nothing but
17 watching television all day, and is up on the
18 Canadian border with a family in New York City, and
19 there's really not sufficient psycho-social services
20 for someone and we have to be aware of this and
21 recognize that the prisoners are not able to get
22 these services inside the prison.
23 Finally, I'm just going to mention that
24 for many stages releasing somebody early will mean
25 saving substantial amounts of money. Unfortunately,

2 in all the five states that I surveyed for this
3 testimony in the federal system, they're just not
4 doing enough and the savings are very minimal, but I
5 think states could buy into making an argument at
6 least that they could save at least 50 percent of the
7 cost of the medical care delivery of people who are
8 released.

9 I just want to talk about a telephone
10 survey that I did on a number of institutions. I
11 found that very few people out there knew what was
12 going on in some kind of national perspective. In
13 states where there's executive clemency, the
14 governors are not issuing clemency.

15 Again, the statutes are really being
16 underutilized for people who are sick with AIDS or
17 not being utilized at all. Then there's temporary
18 release statutes that some of the correction
19 departments have, which sort of let you be able to
20 get a prisoner out of the system into getting some
21 care in an outside hospital or hospice, but in fact
22 it's somewhat short termed and some departments try
23 to push it as far as they can because they have no
24 mechanisms that are available to them to get people
25 out if they so want to.

And I think that in New York State we had an interesting situation where we had a medical parole bill that's been kicked around for three or four years, and it was a bill that would enable prisoners to be released prior to serving their minimum sentence. It's gone through a lot of revisions. The final revision, we were told this year, if everybody was quiet, we were told it would be passed through on the 11th hour. It didn't get anywhere, it was an election year and I really think our leaders in the state and federal system do not have the courage to really push forward on the kinds of mechanisms that would enable early release for prisoners.

Finally, I have given you some of the recommendations, policy recommendations that I would ask you to consider and make in terms of early release for very seriously ill prisoners with AIDS. I have listed them all here and I would be glad to entertain any questions you have about them.

Thank you very much.

DR. OSBORNE: Thank you.

MR. SANCHEZ: Good afternoon, and I thank you for the opportunity to participate

2 in these hearings, and also the fact that this is
3 actually happening and looking at a particular
4 segment of our population that's overlooked many
5 times, and it's good to see some familiar faces that
6 I remember from the round table discussions in
7 Washington, so hello.
8 What I would like to do is maybe, because
9 as the last person speaking, I get this feeling that
10 you heard it all and know all the numbers,
11 percentages and statistics and so forth, so let me
12 try to focus in on a few things.
13 At the Commission, I supervised the area
14 of advocacy, and in doing so, the area that we have
15 seen the fastest growing increase has been in prison
16 related complaints, to the extent now that we are
17 about to initiate the HIV prison project that I hope
18 to be heading soon, so there's a lot of work.
19 I think that in the area of AIDS, doing
20 work in prison is still one of those pioneer type of
21 grounds where there's still a lot of work to be done.
22 At the Commission, we handle approximately
23 600 complaints of HIV related discrimination on a
24 yearly basis. And other than--the greater activity
25 other than prison is seen only in the areas of

2 employment housing and hospital setting. I think
3 that there's good reason to enlarge the scope of our
4 discussion today to include all persons being
5 released from correctional facilities, and I say that
6 for several reasons. The number of men and women
7 that are being incarcerated in New York State is
8 staggering, and the numbers are growing and they're
9 talking about building more and more prisons.

10 As I've told you in my testimony, I am an
11 ex-offender, I served about seven years in the New
12 York State criminal justice system, I then worked for
13 the Fortune Society, it's an ex-offender organization
14 for nine years doing counselor and court liaison type
15 work. I go into three facilities on a monthly basis,
16 two males and one female. I go in to do AIDS-related
17 discrimination training, and what I really do is a
18 lot of AIDS 101 and providing them with the essential
19 and basic information that they just don't have.
20 There's a lot of ignorance and misinformation and
21 fear still going on within the different facilities
22 that I go to.

23 Prisoners and ex-offenders are in my
24 opinion two of the most stigmatized groups in
25 society, so what happened with AIDS is you're

2 compounding an already stigmatized group of being an
3 ex-inmate, and so the fears and the stigma make it
4 that much more difficult for a person, and there are
5 sizeable disadvantages.
6 People are still being released from
7 prison with $40 a bus ticket and the Office of
8 Central Parole where you go and report, and beyond
9 that, there's really not that much happening for that
10 person, and then also for the family members, we
11 respond a lot of times to complaints from family
12 members of prisoners that are symptomatic or have
13 AIDS, and family members for the most part are
14 uninformed about the prison experience and are
15 worried about people that they have incarcerated.
16 They're almost never informed about the health status
17 of the inmate who is being released into their care,
18 into their home, nor are they involved in any type of
19 way with the post release process or at least the
20 resources and organizations in terms of who to turn
21 to, how to protect themselves, all the basic
22 information that a person would need to deal with
23 that situation.
24 Cathy touched on the transfer, the
25 distance that people who are incarcerated with AIDS

2 and the lack of access the families have to people
3 who are behind the wall and are like 400 miles away
4 and don't have the resources, don't have the means by
5 which to visit that person, so we get a lot of
6 complaints in that area as well.
7 And the issues are and concerns are
8 magnified for Latino prisoners who often lack the
9 ability to communicate their concerns in English and
10 there's clearly an underrepresentation of bilingual
11 staff within the correctional system. And there is
12 no support systems in place to address the needs of
13 family members for whom English is a second language
14 as well.
15 Persons returning to the community from
16 prison often have been given little or no information
17 regarding AIDS, and safer sex and this places them, I
18 think, at a greater risk for HIV infection, simply
19 because sex and drugs are two of the most powerful
20 attractions for someone being released from prison.
21 I think there's a pressing need to
22 institute mandatory discharge planning procedures for
23 prisoners with AIDS. The discharge of these inmates,
24 I think, should be as carefully planned as the
25 discharge of patients from a hospital. Yet at this

2 time there's no such system in place.

3 The medical records of inmates are not at
4 their disposal when they're released, nor are they at
5 the disposal of the New York City HRA, Human
6 Resources Administration, which is responsible for
7 providing suitable housing arrangements at an
8 appropriate level of care for ex-inmates with AIDS.

9 Absolutely no consideration is given to
10 these imates' illness or need for hospitalization.
11 They are released without consideration for their
12 future needs. Furthermore, the requirement to
13 confirm that an ex-inmate's housing needs has been
14 suitably met has been relaxed.

15 The result has been that inmates that are
16 HIV symptomatic are being discharged into public
17 shelters in conditions which are worse in many of
18 them than what they left in prison. Public shelters
19 are not being designed for people with AIDS, are
20 completely inappropriate residences for anybody with
21 symptomatic HIV infection.

22 The Fortune Society found that 99 percent
23 of their clients who reported being released from
24 prison to the shelter system have opted to live in
25 the street, because shelters are more oppressive and

2 unsafe than the prison they left behind and these
3 inmates, like others, reenter society armed only with
4 what the correctional administration has provided
5 them, again the $40 and the address of the parole
6 officer.
7 After release, inmates with HIV infection
8 suffer the same range of problems facing poor HIV
9 infected New Yorkers, but with the added stigma of
10 being ex-cons. They must rely on emergency rooms for
11 primary medical care and thus are not able to take
12 advantage of early intervention and never experience
13 the continuity of care. That's very important.
14 Post release prisoners must also seek
15 employment and often have a real shaky housing
16 arrangements or no arrangements at all. Seeking
17 these basics of life, they are very likely to
18 experience HIV related discrimination.
19 HIV related discrimination problems in the
20 parole process have also been reported. I've done
21 some trainings also with some parole officers, and
22 it's just interesting. The stigma that's attached to
23 AIDS, just so incredible where parole officers feel
24 pressures from their peers as a result of working
25 specifically with parolees with AIDS.

2 Breaches of confidentiality and other HIV
3 related abuses within the system continue to be
4 reported. However, indicating the need for regular
5 updated AIDS information to be provided to this group
6 also, talking about parole officers now.
7 Following the ex-inmate as he or she
8 attempts to obtain necessary services with little or
9 no financial resources, we see these individuals
10 encountering HIV related discrimination again and
11 again.
12 About 12 percent of all HIV related
13 discrimination complaints occur in the hospital
14 setting and another 8 percent that are reported at
15 the Commission occur attempting to seek government
16 benefits, both likely places for ex-inmate contact.
17 HIV-related discrimination by clinics and drug
18 treatment facilities is also high and many doctors
19 and dentists discriminate against the HIV infected.
20 Add to this the increased discrimination faced by the
21 ex-offender and the scope of AIDS-related
22 discrimination for released inmates becomes clear.
23 Thanks for listening, and whatever
24 questions you may have, I'll do my best to respond.
25 DR. OSBORNE: Thank you very much? Are

2 there questions from the Commission? Harlon.
3 COMMISSIONER DALTON: I was struck bring
4 the fact that both of you, Cathy in your written
5 testimony and Romeo, both written and oral testimony,
6 talked about the need for discharge planning.
7 I guess I'd be curious about what kind of
8 discharge planning is done now for any inmates coming
9 out of the New York State system or the other systems
10 that you surveyed, Cathy, and I wonder whether
11 requiring discharge planning prior to compassionate
12 release is a way of making sure it doesn't happen.
13 On the other hand, obviously, releasing
14 people who have AIDS and who are sick without some
15 kind of planning for their housing, for making sure
16 their medical records follow them, that their
17 families, if that's where they are know what to do is
18 not a very happy prospect either, so I wonder if you
19 could talk a little more about that.
20 MS. POTLER: Well, in New York State there
21 just isn't, in New York State there's not enough
22 discharge planning going on, clearly. People are
23 being released, and they don't have what's known as
24 the famous N-11-Q form, which is sort of your
25 entrance into the whole social service agencies,

2 which enables you to get extra money for rent, which
3 enables you to all sorts of human services, as well
4 as Medicaid. So it's a problem.
5 We're in the process of working with the
6 Department on this, but you really need to have more
7 than just making a form available, you need to have
8 people who can help as people are about to be
9 released, walk them, not by hand, but help them
10 through the system, and this just isn't being done.
11 In New York City, for instance, we're even
12 finding, I mean, people being dropped off on the
13 other side of the 59th Street Bridge at two, 3:00 in
14 the morning, people who are in wheelchairs being
15 released at ten of five on a Friday afternoon with a
16 call from the doctor at Rikers Island saying, "What
17 can you do for this person and we also need the
18 wheelchair back, by the way."
19 You know, it's an enormous problem and I
20 think that while in the New York City system there is
21 more of an active desire to get some of the prisoners
22 who should be released either out on a bail reduction
23 application or on their own recognizance or those who
24 have already been sentenced, to get them out more
25 than any other system that we surveyed. Still, there

2 needs to be some money put in by the City or the
3 State to be able to provide the adequate kinds of
4 counselors that are needed to do the proper discharge
5 planning and I think it would be wrong to discharge
6 anyone who is very sick with AIDS to most of the
7 shelters here in New York City, and I guess that
8 would be true for most major cities in the country.
9 MR. SANCHEZ: Just to add to that, Cathy
14
10 and I are involved in trying to make that happen.
11 What we did is actually got Parole, Corrections, some
12 community based organizations, we had everyone in one
13 room and the head people of the Division of AIDS
14 Services for HRA and kind of let's talk about this,
15 let's develop some mechanisms; you meet this person
16 and talk and to each other and work this out. It
17 doesn't make sense for a person--this is an actual
18 call that I received, I was working with this woman
19 doing some advocacy for her, she was incarcerated at
20 Bayview, then was at St. Clare's, had some issues
21 there, that's how we initially met.
22 Then when I went to--I would go to Bayview
23 with these presentations, I would see her, she would
24 be part of that group. Parole knew in advance, like
25 three months in advance when the person was going to

2 be released. Bayview is a facility that's on 20th
3 Street and 11th Avenue in Manhattan. The Human
4 Resources Office Division of AIDS Services is on 13th
5 street in Manhattan, and why is it that this woman
6 was discharged, I got a call from her on 4:45 on a
7 Friday afternoon, that she was discharged, no plan
8 whatsoever, she was sent to HRA at the last minute,
9 no preparation of the N-11-Q form, nothing, sent to
10 this SRO hotel in the Bronx with crackheads, broken
11 door, sewage backed up, no running water. This is
12 the condition that this woman was discharged to.
13 There was no plan.
14 So we kind of like used that as an
15 example. Hey, you need to do a much better job for
16 people to send someone out. No one should live in
17 that condition, but much less someone with twelve T
18 cells.
19 We're trying, but there really needs to be
20 a focus, and I don't think that necessarily one
21 should replace the other, and maybe have them both
22 going, you know. There has to be a way.
23 Again, going back to the stigma, the only
24 release mechanism that's available is the executive
25 clemency and the Governor has not issued that to

2 anyone with AIDS, but the stigma and the politics
3 behind that, so, yes, there has to be a medical
4 parole bill, I think, hopefully, it will happen and
5 discharge planning should be in place as well.
6 MS. POTLER: I would also like to say that
7 through our program, which is a very modest program
8 providing services for families and friends of
9 prisoners with HIV, we have been able to get a lot of
10 paperwork in place, so it's not hard to do, it's a
11 rather easy process, it just needs to have a priority
12 placed upon it for people to push and desire and want
13 people to get out.
14 DR. OSBORNE: Well, thank you very much
15 for your testimony, your patience in coming so late
16 in the day, we really appreciate the input.
17 We have two people who have requested to
18 utilize time on public comment. First, Anna Forbes,
19 and we'll ask if you could keep your comments to
20 three minutes.
21 MS. FORBES: Good afternoon, I want to
22 thank you very much for giving me this opportunity to
23 add my comments to this hearing.
24 I represent Action AIDS, which is a
25 community based organization providing services now

2 to 400 people in Philadelphia living with AIDS and
3 HIV disease.
4 We've been offering our services to
5 incarcerated people with AIDS since our inception in
6 1986 and our staff and volunteers have worked with
7 people in all five of our local correctional
8 facilities.
9 I'm here today to ask you to remember that
10 community based AIDS service organizations have an
11 important role to play in the fight against AIDS on
12 the inside, and actually this is perfect timing for
13 me, because I think my comments here will pick up a
14 number of issues that were just addressed.
15 The Commission by affirming the importance
16 of the role of the community based organization can
17 substantially bolster our ability to do what we do
18 best, provide highly individualized caring assistance
19 to people living with AIDS. We are in fact one more
20 resource that can be marshalled to address these
21 needs.
22 Organizations like Action AIDS all around
23 the country can voluntarily offer a level of one to
24 one attention over long periods of time that medical
25 personnel educators and social workers, no matter how

2 dedicated, cannot supply. The resource that we offer
3 contributes in two ways to breaking the isolation
4 that's often experienced by people living with AIDS.
5 The first way is by giving the
6 incarcerated person someone with whom it is safe,
15
7 quote-unquote, to discuss AIDS. People on the inside
8 often feel they can't talk about the diagnosis with
9 anyone other than medical or social service staff
10 whom they often see only very briefly, an AIDS buddy
11 or case manager from a community based organization
12 gives the individuals someone with whom concerns
13 about AIDS can be discussed at length.
14 The second way in which we assist in
15 breaking isolation is by helping family members on
16 the outside to understand what an AIDS diagnosis does
17 and does not mean. Family members sometimes shy away
18 when an individual is diagnosed. Their own fears of
19 infection or misinformation about AIDS can make it
20 hard for them to continue to offer support to the
21 incarcerated person.
22 Because AIDS service staff and volunteers
23 can establish contacts with both the individuals on
24 the inside and the family members on the outside,
25 they could help to maintain relationships during this

2 very difficult period. In addition to providing the
3 desperately needed support to people during
4 incarceration, AIDS service organizations are often
5 ideally situated to assist paroled individuals and
6 this is the topic obviously that was just being
7 discussed.
8 People with AIDS frequently need immediate
9 access to a whole range of AIDS specific services.
10 Just a few of the questions that our case managers
11 ask people with AIDS who are being paroled include,
12 "Where are you planning to get your medical care and
13 how will you pay for it?" Newly paroled people with
14 AIDS don't necessarily have a lot of time in which to
15 get a doctor lined up and a medical assistance
16 application in process, because of course a medical
17 crisis can hit at any time.
18 If you're a newly paroled person with
19 AIDS, where will you live; will your family let you
20 move back in; do they know you have AIDS; are they
21 prepared to deal with it; do they have the support
22 and the basic infection control information they need
23 in order to live with you comfortably?
24 If you have a drug habit and have AIDS,
25 it's extremely dangerous, obviously, to resume drug

2 use. Have you arranged to get yourself enrolled in a
3 drug treatment program; will you actually follow
4 through with the treatment plan; will it help to have
5 a buddy while you're going through this to make sure
6 you follow up on your intention to get into
7 treatment?

8 These are a few of the issues that we can
9 address with individuals with AIDS who are coming out
10 on parole. We have found that our staff and
11 volunteers can be immensely helpful in resolving
12 these concerns. In fact, one judge stipulated
13 maintenance of contact with Action AIDS as a
14 condition of parole for one of our clients.

15 Given that the benefits of involving
16 community based organizations in programs designed to
17 address the needs of incarcerated people with AIDS
18 are fairly obvious, you may wonder why I came today
19 to recite them to you.

20 The reason is that in order to take this
21 role AIDS service organizations first need to be
22 allowed access to people in prisons and jails, and
23 this in our experience has been a tremendous
24 stumbling block. No one, as you know, can be
25 admitted into a correctional facility without consent

2 of the administrators. In Philadelphia we've been
3 fortunate in that we've had a high level of
4 cooperation with the Philadelphia prison system
5 staff, but other organizations in Pennsylvania and
6 around the country have not had the same level of
7 cooperation.

8 The adminsitration of one of the
9 correctional facilities to which we sought access
10 told us they had no residents with AIDS, but they
11 would notify us as soon as they did. We called back
12 regularly every month to see if our assistance was
13 needed, then they started to tell us that they had in
14 fact had residents with AIDS, but those people were
15 either all released or had died.

16 Clearly, we were experiencing an access
17 problem.

18 DR. OSBORNE: Let me ask you to finish up
19 fairly quickly, if you can. We are getting short of
20 time.

21 MS. FORBES: I wanted to say, really, my
22 point is I wanted to ask the Commission to recommend
23 specifically that directives be issued both at the
24 federal and state level directing prison
25 administrators to make contact and establish a

2 working relationship with their local AIDS service
3 organization. We found in Pennsylvania that we were
4 successful in getting the Pennsylvania Department of
5 Corrections to issue such a directive.
6 We feel the access problems we're facing
7 really cannot be overcome without an explicit
8 directive to prison administrators to establish that
9 contact.
10 Thank you very much.
11 DR. OSBORNE: Thank you. That's a
12 thoughtful comment. We appreciate it.
13 The other public comment will be coming
14 from Judy Greenspan.
15 MS. GREENSPAN: I'll make it really short,
16 because I'm probably almost as tired as you are.
17 I know there's been a lot of discussion
18 about testing and segregation, and I just wanted to
19 be very concise and ask something of you. It would
20 be very helpful in the correctional system if you
21 came up with recommendations specifically dealing
22 with HIV testing and segregation, and I would propose
23 that you come up with guidelines that suggest to all
24 correctional systems that there not be any mandatory
25 HIV testing, that the only testing be voluntary,

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2 accompanied always by pre and post test counseling
3 for people who test positive and negative, and I
4 would call your attention to a very excellent study
5 that was done by the Oregon Department of Health and
6 the Oregon Department of Corrections and it was
7 reprinted in the American Public Health Association
8 Journal, "Testing for Prisoners: Is Mandatory
9 Testing Necessary," and you may have copies of it,
10 but I think it would be very, very important.
11 As far as segregation is concerned, just
12 to clear up any ambiguities, we would propose that
13 the ACLU National Prison Project would propose that
14 there not be any segregation, and I know there are
15 some terms thrown around, "medically indicated
16 segregation," that type of thing. There really is no
17 such thing as "medically indicated segregation."
18 There is medically indicated hospitalization for sure
19 for people who are sick and we would advocate really
20 that HIV in prison be treated the same way as it's
21 treated on the outside.
22 We don't segregate people on the outside,
23 we shouldn't segregate people in prison. If someone
24 is sick, they should be able to go to a hospital
25 where they get competent care and when they finish

2 with their bout of whatever it is, that they be
3 returned to the prison population. Of course, this
4 is going to take education for prisoners and also for
5 staff, but we believe that the only rational policy
6 is no mandatory testing, and no segregation.
7 DR. OSBORNE: Thank you very much.
8 And thanks to all of you for your
9 attention and I think it's your turn to declare this
10 closed.
11 MS. BYRNS: I declare this closed.
12 We're adjourned.
13 (Time noted: 5:15 p.m.)
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